



End of Life

Annual Report of the
Director of Public Health for Somerset 2017

Introduction

Last year I showed how dramatically health has improved over 80 years in Somerset. Infectious diseases that were once major killers have been almost eliminated through improved hygiene, sanitation and vaccination. These changes have meant that we are generally living longer, and our deaths are more likely to come from lifestyle related conditions such as cardiovascular disease and cancers and those usually associated with increased age such as dementia. Many people live for a long time with these conditions, and the 'end of life' can be an extended period. This is a difficult time for the individuals concerned, and for their families, and the health and care needs are complex.



This is not a guide to providing end of life care. In this report I want to play my part in raising the profile of this vital part of life. Looking at end of life from a public health perspective, I want to describe:

- Describe the **trends** in the numbers, causes and places of death in Somerset
- Consider how end of life is currently supported in the county overall, and how individuals, families, health and care services can contribute to making end of life as **peaceful and dignified as possible**
- Highlight how the whole health and care 'system' can **work together** to provide the best possible care.
- Emphasise the role of **compassionate communities** in providing wider support.
- Encourage us all to **prepare** for the end of life, making preparations such as Power of Attorney and Advance Care Plans.

Public health is concerned with the health and wellbeing of the whole population from pre-pregnancy to end of life. Just as we look to give every child in Somerset the best start in life, and adults to have the opportunity to be healthy and productive for as long as possible, so the final months should be viewed as contributing to the overall quality of a life well-lived.

The data supplement that accompanies this report can be found at the following link:

<http://www.somerset.gov.uk/organisations/departments/public-health/>

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SECTION 1 – Death in Somerset

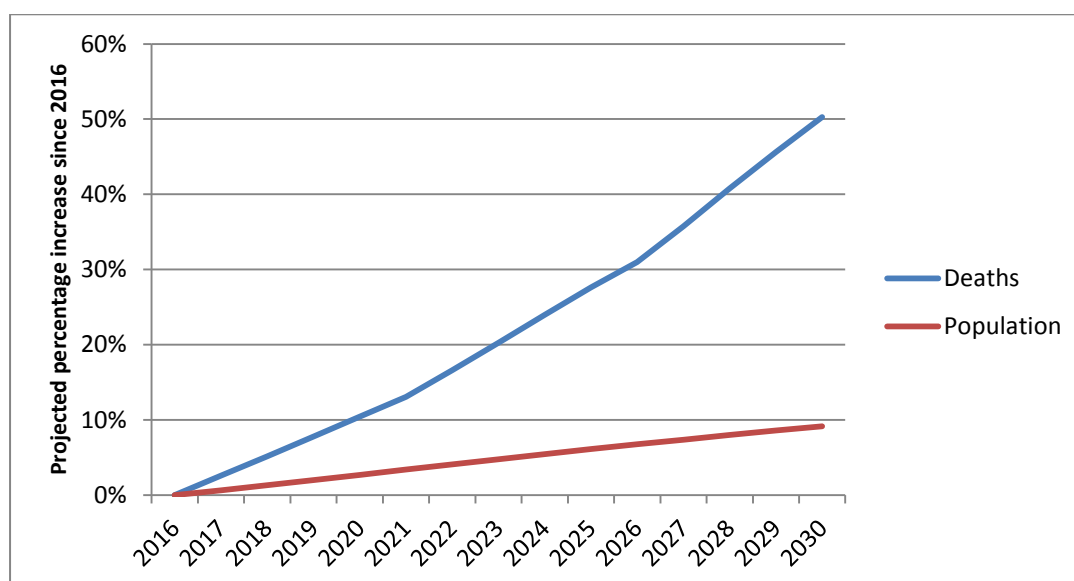
In this section we will look at some of the facts and figures about death and dying in Somerset. Examining these statistics can help us get a better understanding of the scale and nature of the issue and help guide our response.

Numbers of deaths

In last year's report I described Somerset in the 1930s. Then there were about 3,700 deaths each year in the current county area. Although life expectancy has risen considerably since then, that number has risen to about 6,115 deaths in 2015 (the last year for which we have figures). This is simply because of the increasing population, which has grown from just over 290,500 in 1936 to 545,400 in 2015, an increase of 88%. The number of deaths has only risen by 41%, because people now live much longer than they did then.

When we look at likely trends in the future, the ageing of the 'baby boomer' generation born after 1945 means that the numbers of deaths each year is expected to rise dramatically, and much faster than the population total.

Figure 1: Projected Numbers of Deaths (source: Public Health Somerset)

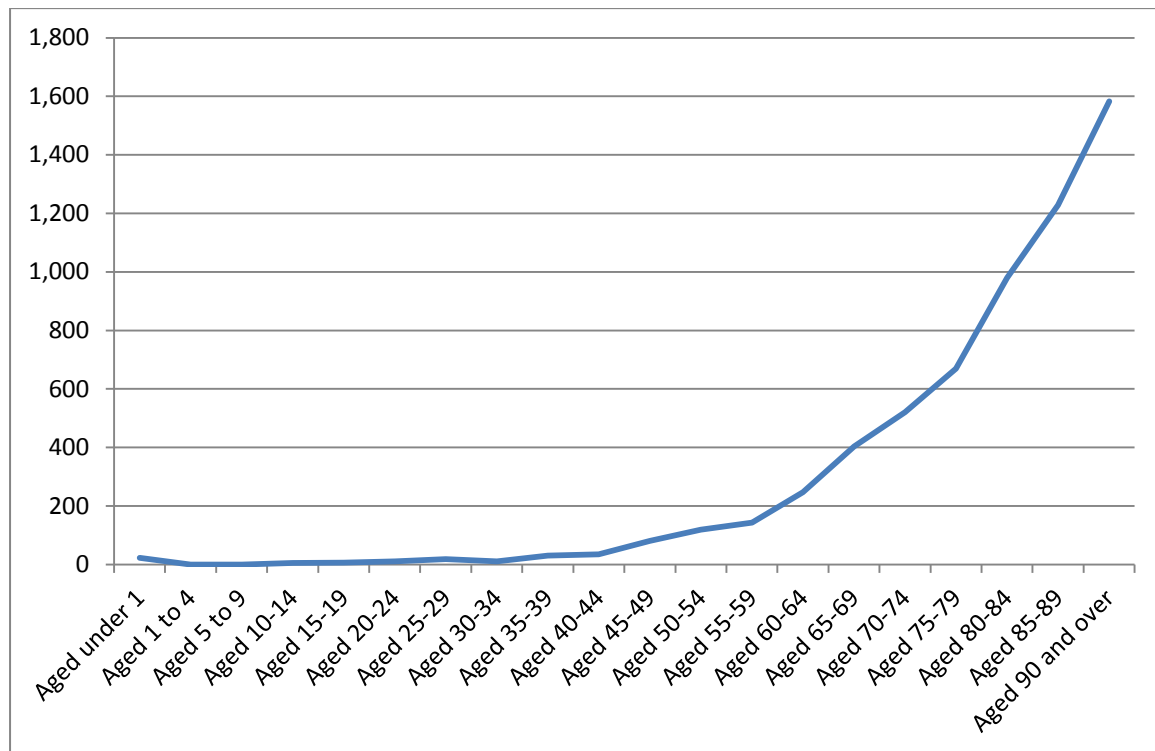


There is clearly a great deal of uncertainty in any projection of this sort, but this graph demonstrates that simply in terms of numbers, end of life care will become a more prominent issue for health and care in Somerset over coming years. There were 6,020 deaths in Somerset in 2016; that is projected to rise to over 9,000 by 2030.

Age at death

Figure 2 shows the age at which people died in Somerset in 2015. Nearly three quarters of all deaths were of people aged 75 or older, and more than 90% were of people aged 60 and over. Only 1.7% were of people aged under 40. In this report I will concentrate on the care of older people approaching death. This is not to overlook the needs of young people – many of which are the same of course, but I will focus on the large majority of those reaching the end of their life as, for this issue, this is where the greatest challenge for the county lies.

Figure 2: Age of death in Somerset 2015



Causes of Death

Figures 3 and 4 show the leading causes of death in Somerset in 2015 for men and women. Cancers, circulatory diseases and heart disease are the main causes of death in Somerset, mirroring the national prevalence. By sex, the broad patterns are similar, although cancer is the leading cause for men, and circulatory diseases for women. It can also be seen that diseases of the nervous system – mostly dementia and Alzheimer’s disease – are more significant causes of death for women than for men. Notably, many of the conditions that cause death may only do so after a protracted period of illness, with major implications for end of life care.

Figure 3: Leading causes of death, Men in Somerset 2015

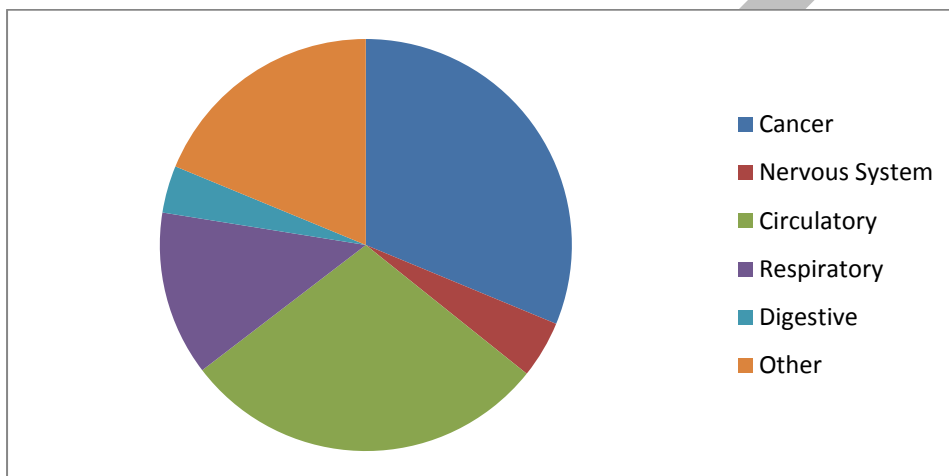
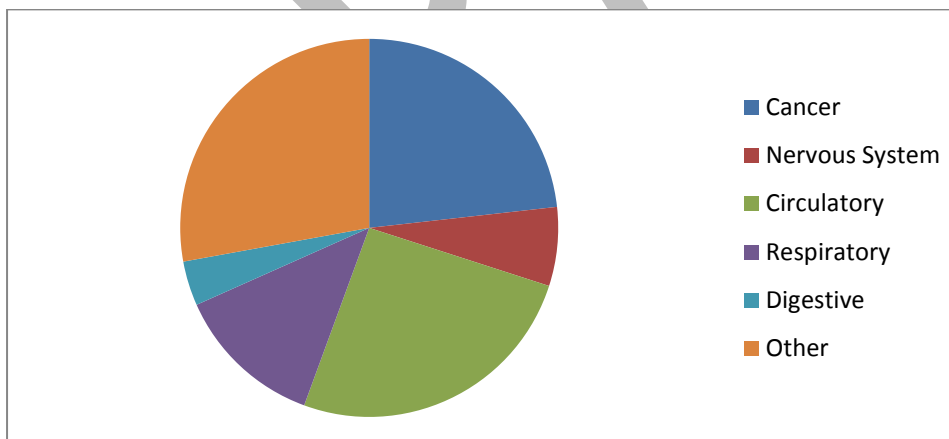


Figure 4: Leading causes of death, Women in Somerset 2015



Figures 5 and 6 below looks at the differences in the causes of deaths in Somerset over the past 10 years. There were 5,482 deaths in 2007 and 6,042 in 2016. The key points to pull out from this is that the proportion of deaths that were attributed to dementia (including Alzheimer’s) in 2016 was 13%, more than double the percentage from 2007 of 6%. Those attribute to circulatory disease, coronary heart disease and stroke accounted for a smaller proportion of deaths in 2016 than in 2007

Figure 5: Proportion of deaths by underlying cause of death 2007-2016

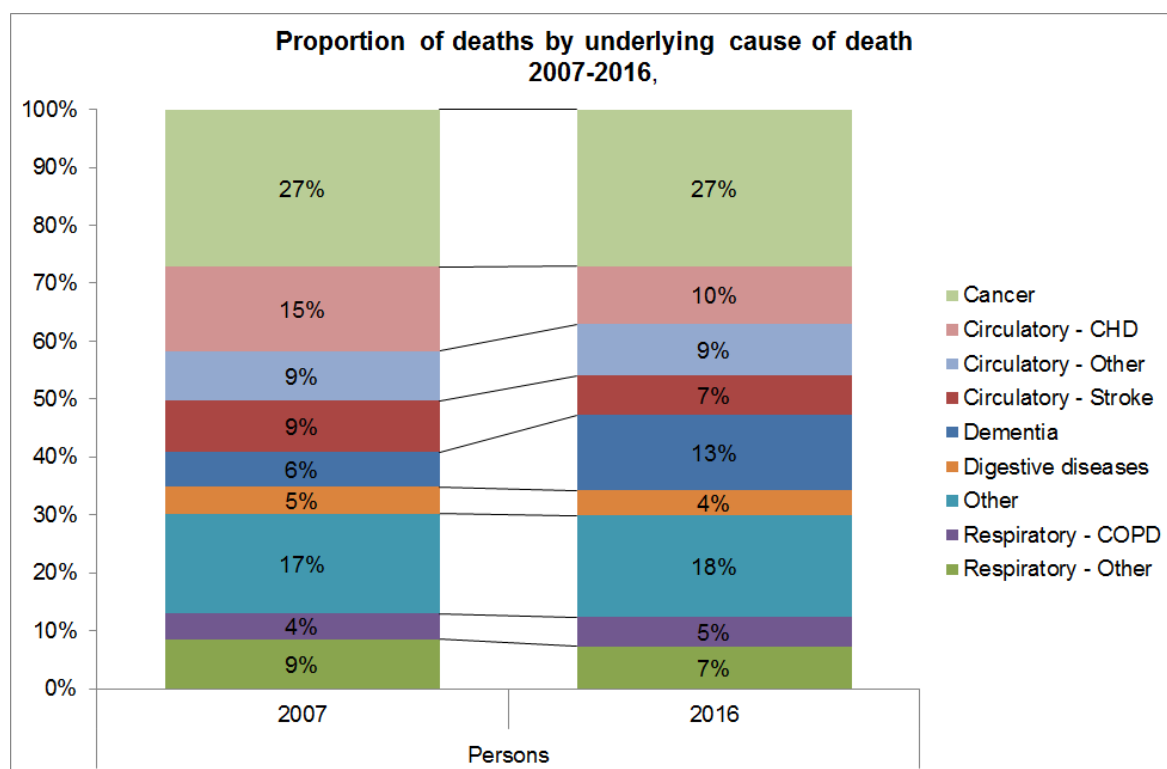
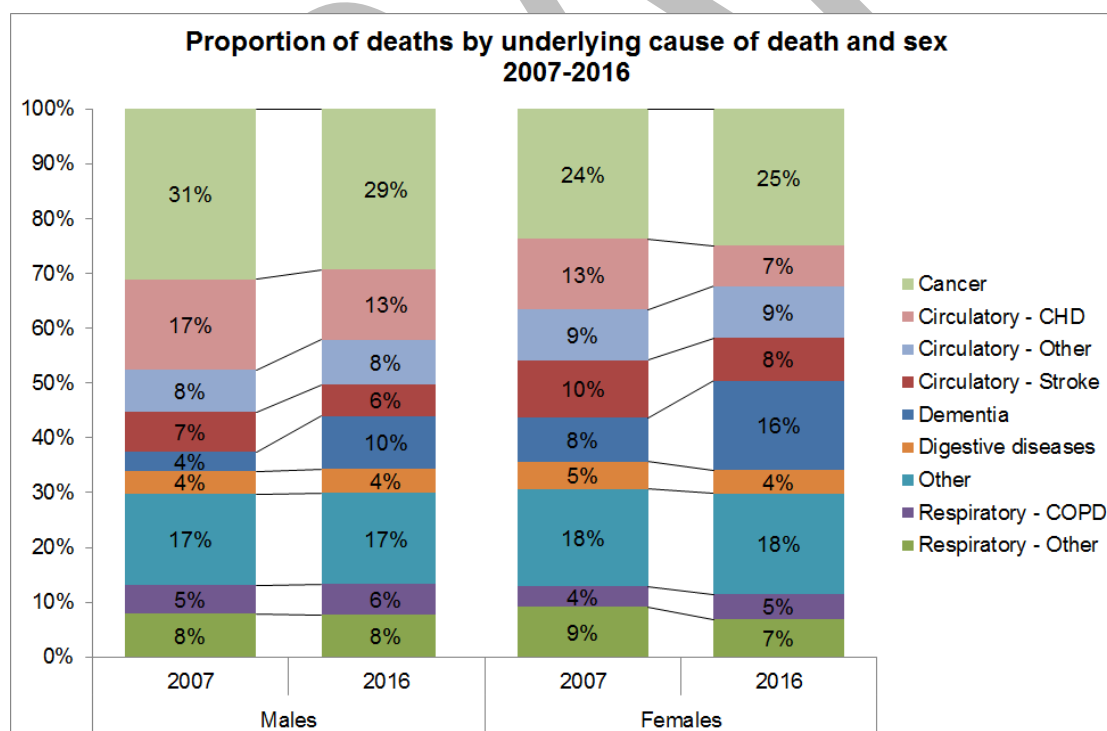


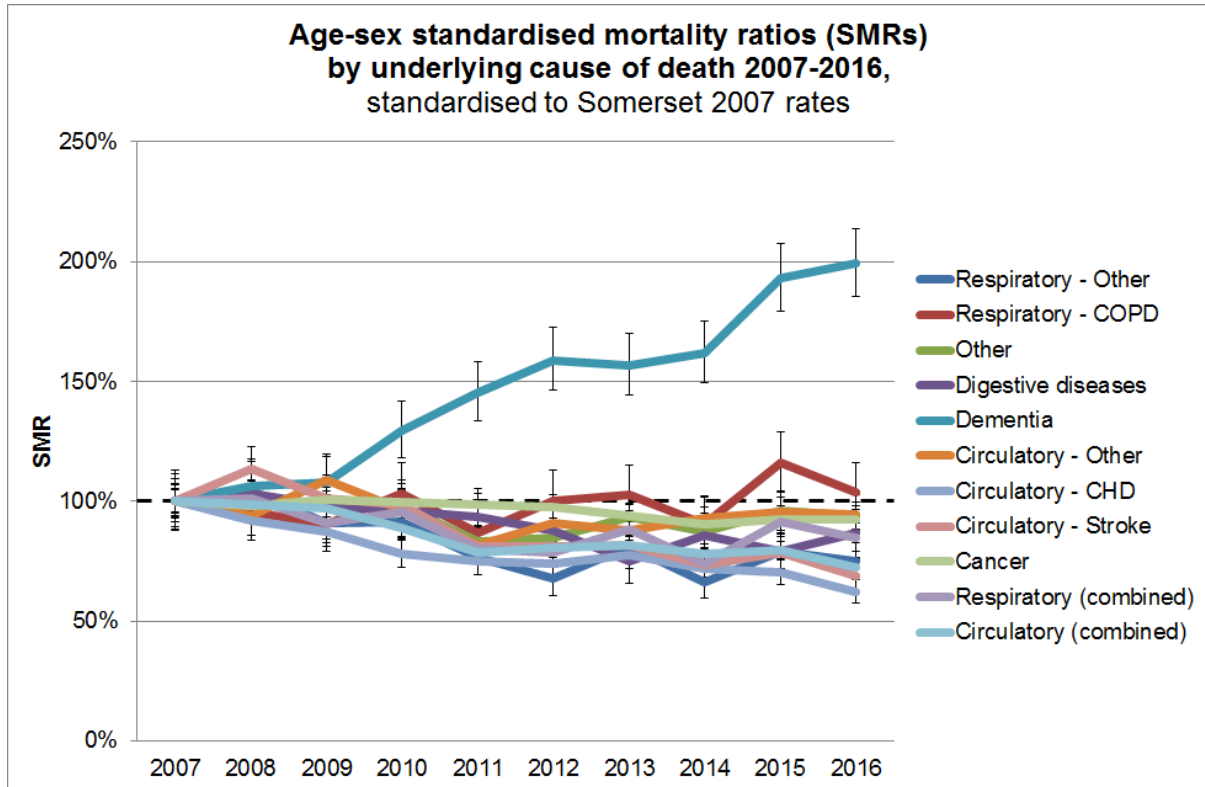
Figure 6: Proportion of deaths by underlying cause of death and sex 2007-2016



Source: Primary Care Mortality Database Copyright © 2017, re-used with the permission of The Health & Social Care Information Centre. All rights reserved. Deaths used in the production of these charts that occurred prior to 2015 and prior to 2011 have been adjusted. This is to account for coding changes introduced by the Office for National Statistics (ONS) at these times.

By standardising the data to the 2007 Somerset rates, we can consider how many deaths due to each condition would have been expected for the 2016 population size and structure. Figure 7 shows clearly that the dementia mortality rates have been steadily increasing over the past ten years and were around twice as high in 2016 than they were a decade ago. Mortality rates due to all other underlying causes have significantly declined over this period.

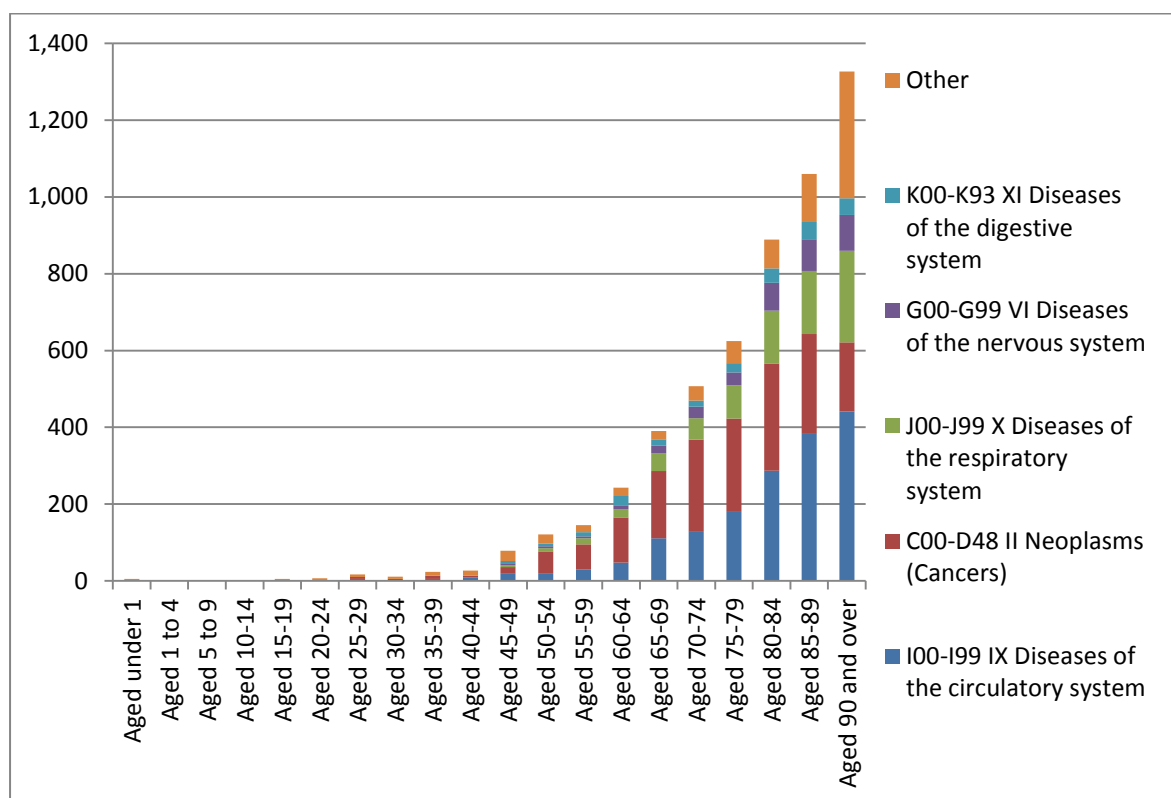
Figure 7: Age-sex standardised mortality ratios



Source: Primary Care Mortality Database Copyright © 2017, re-used with the permission of The Health & Social Care Information Centre. All rights reserved and Office for National Statistics (ONS) mid-year population estimates.

Figure 8 shows the same broad categories of cause of death by age for men and women together in the same graph. Cancer is the biggest killer for people aged between 50 and 80, and at older ages circulatory and respiratory disease and diseases of the nervous system rise in significance.

Figure 8: Major causes of death in Somerset by age, 2015 (Source: ONS Mortality Statistics)

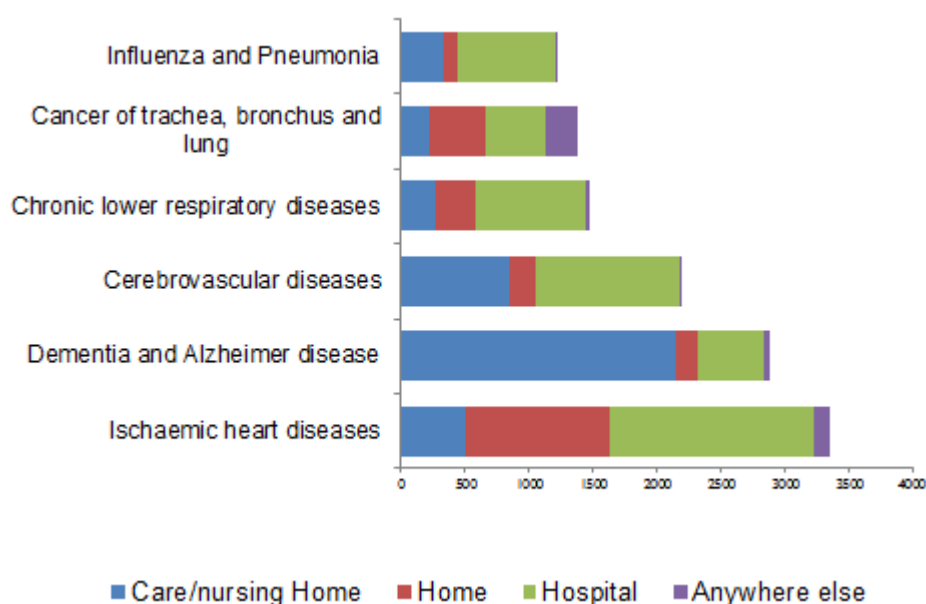


These statistics summarise the number of deaths, age and cause of death per year. Looking at this across the entire population rather than simply by conditions informs the nature of care and support that are needed by people approaching the end of their lives in Somerset. Most of the people in near end of life are older and have long term conditions that people live with for many years until death (which may, indeed, be the immediate result of a different condition entirely).

Place of death

Perhaps most noticeable in Figure 9, looking at the place people die, is that the largest proportion (40%) is in hospital, even though we know that about 66% of people in South West England would choose to die at home, and only about 4% would choose a hospital. And despite falling as a proportion over time, hospital is the most common place of death for those not dying of cancer. In this report, I want to look at ways in which more people are able to die in the place of their choosing. It is also striking that a very large proportion of the dementia and Alzheimer's deaths are in care homes. This situation reflects a number of issues including the nature of the disease and the degree to which support in our communities is able to cope with some of the issues relating to more advanced neurological disease.

Figure 9: Place of death by cause of death



Alzheimer's and Dementia

The rates of dementia are often thought to be underestimated, the number of people with the condition in the county is projected to rise by 75% by 2035 to reach approximately 12,000. In Sedgemoor the number is expected to rise by 83%, compared to an increase of 70% for England as a whole. The relatively low death rate from dementia is likely to be associated with low diagnosis and not recognising it as a cause of death. The process of dying from dementia is different from other conditions as individuals at the end stage of dementia often lose interest in food because they lose their sense of taste and their hunger drive. This can lead to malnourishment and being investigated for a cause of weight loss and admitted to hospital with complications such as infection. It is frequently this that is then documented as the leading cause of death with the dementia often not recognised.

There is a risk that communication problems associated with dementia may mean that such patients suffer more discomfort and pain during the period of end of life, this point can also apply to people with learning difficulties, of course. The drawn out development of dementia may mean fewer people make advance care plans than is the case for people who receive the shock of a cancer diagnosis, for instance, yet the impact on the family can be considerable as the disease affects behavior as it progresses.

The funding system also makes dementia more challenging for providers than, for example, cancer, with a far higher proportion of the costs falling to social care rather than the NHS. That means that it is means tested and costs are therefore more likely to fall on the individual or the family. Whilst there is no cure for dementia, people with the condition may live in steady decline for many years. Patients may require support in the basics of life, putting much of the physical burden, too, on carers within the family. Such pressure, particularly on an ageing spouse coping with his or her own failing health can lead to both needing social care support. With dementia set to increase in coming years this will be a growing challenge for end of life care in Somerset.

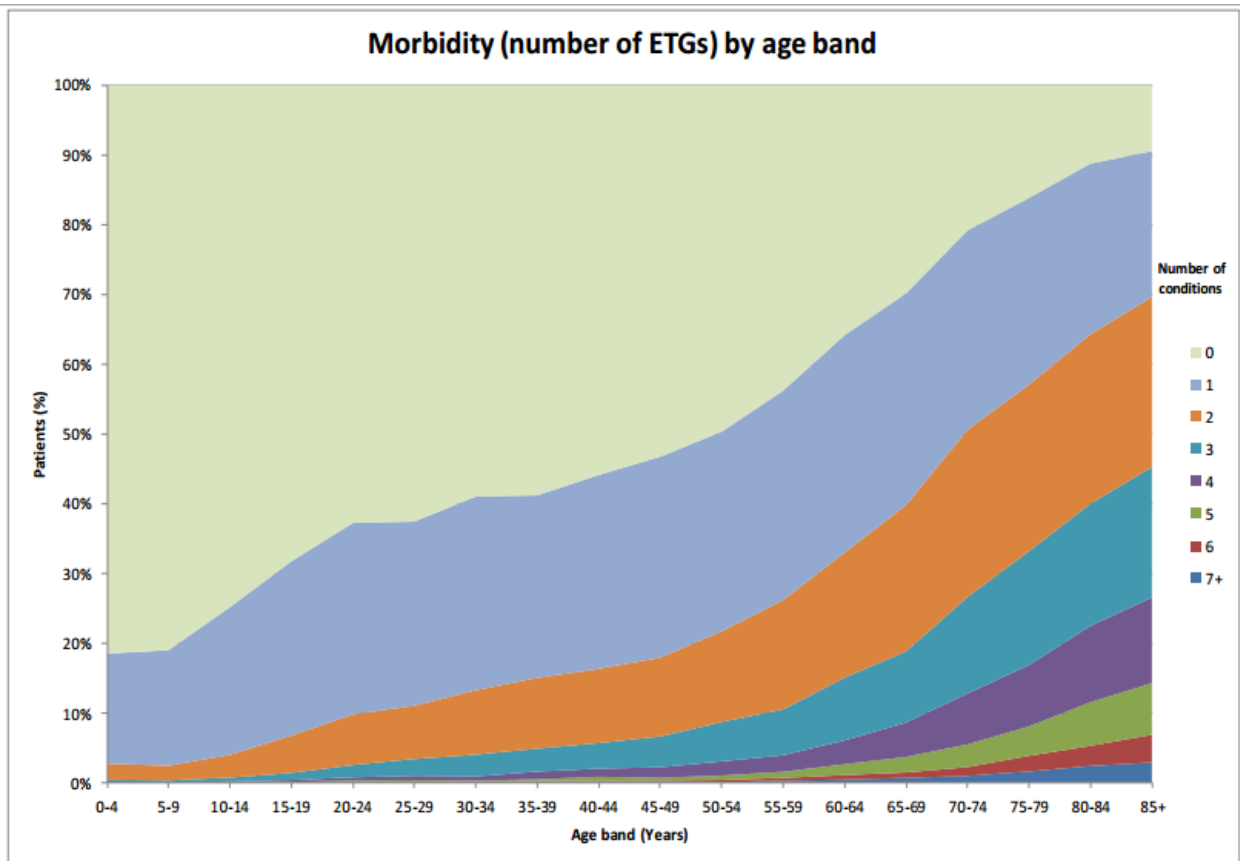
Long term conditions and multimorbidity

When infectious disease was the leading cause of death, there were typically two ways in which illness could run its course. Either someone would recover from the disease, even if with some long term effects, or they would die. In the 21st century, with more deaths from long term conditions such as dementia, cancer and chronic kidney disease, as shown in Figure 2, there are many people who live with gradual deterioration for years. Of course, over such a period it may be that the long term condition is not eventually the direct cause of death.

Perhaps more significantly for treating and managing end of life care, many people will develop more than one condition and show 'multimorbidity'. These patients, often referred to as 'complex', offer significant challenges to treatment because of the interaction between the different conditions or the treatments being provided. As a simple example, taking the medicine needed to manage cancer is far more difficult to manage for someone with dementia than someone without. And as a rather different example, in the past people would often have just 'one shot' at being treated for cancer, whereas now a far wider range of treatments is possible. Radiographers in Somerset report that people with late stage cancer now have different symptoms from people previously and some of those symptoms may have been caused by the treatments that were given 15 or even 20 years earlier.

Figure 10 uses data from the 'Symphony' project to show how the incidence of long-term conditions increases with age. By the age of 70, about half of the Somerset population has a long term condition, and by the age of 85 more than 40% have three or more. As the population structure ages so we can expect more people to have these complex conditions to live with.

Figure 10 Multimorbidity by age band in Somerset 2015



We will return to the issue of multimorbidity in the next section in relation to end of life care.

Despite the huge advances in treating disease, death is one certainty in life and it cannot be indefinitely postponed. Understanding and recognizing the process by which the body turns itself off can avoid intrusive, painful and ultimately fruitless efforts to extend the life of someone close to an expected and natural death.

Summary

This section has provided some background information on deaths, and the significant reasons for deaths, at a population level. End of life is something that all families have to face at some point. It is often an emotional and stressful time, just as birth often is, but there are things we could do as a community and as a health and social care system to try and reduce the impact of end of life and make it as dignified and peaceful as possible. Achieving this is absolutely better for the individual, the family and the system. I now want to describe what end of life care is, before considering what more we could do in the future to ease the experience of end of life.

SECTION 2 - End of life care

Evidently, those facing the end of life need support of many kinds. Some is medical, some is emotional and some practical. The burden can be so heavy that the carers themselves, particularly family members, can need their own support. In this section we will look at an overview of the end of life care provided in Somerset and give a brief overview of the types of help that can be provided before considering whether we can do more to make end of life care in Somerset as dignified and peaceful as it can be.

We know that the majority of people would prefer to die at home if they could, and hospital is the least preferred place of death; despite this, less than half (48%) of people actually do die at home in Somerset. We need to consider why this is the case? Firstly, it may be because the death is sudden and unexpected, and the patient is taken to hospital for urgent treatment. Such cases are sadly inevitable. Secondly, the patient, carer or family may feel more secure in hospital knowing that professional care and treatment is nearby and always on call, especially for conditions such as chronic obstructive pulmonary disease (COPD) which can exacerbate rapidly. For all the preparations made in advance, patients and family may find that the illness simply cannot be treated at home: changes in behaviour, or loss of bladder and bowel control, can lead to a serious reassessment of need. Thirdly, some deaths might have come about because the patient's wishes were not made clear in advance, or were not known to those responsible for their care at the end of life. In these circumstances someone may be taken to hospital and admitted as an emergency for treatment that may add little to the length of life. This issue is considered in more detail below.

End of Life and admissions to acute and community hospitals

An admission to hospital can be, literally, life-saving. It is though, despite the efforts of many, often not a pleasant event, particularly if it is an emergency admission. For someone who is close to death with a long-term, life-threatening condition, it may be a source of unnecessary suffering for little gain. We have looked at the patterns of admission for people in the last year of their lives, the large majority of which is direct to acute hospitals. This helps us understand what factors beyond immediate clinical need are involved, and suggests ways in which more rounded, 'whole person', care might be possible.

There were an average of 3.2 admissions to hospital (planned or emergency admission) in the year prior to death for all people who died in 2013-2015. Only 20% of those who died did not have an admission in the year prior to death. Excluding those with no admission, the average number of admissions in the final year was 4.1. People who died during 2013-15 spent on average 22.4 days in hospital in the year prior to death.

For *emergency* admissions only, there were on average 2.3 in the year prior to death for all those who died in 2013-2015, although that includes 37% with no emergency admissions. Excluding those without emergency admissions, the average was 3.7 in their last year. Those people who died during 2013-15 *and* had an emergency admission spent an average of 27.5 days in hospital after they were admitted.

Figures 11 and 12 below show the patterns of emergency admissions for the main condition-related causes of death. For all conditions, except Alzheimer's and dementia, the majority of patients had at least one emergency admission in their last year of life.

Figure 11: Percentage of patients never admitted as an emergency in last year of life

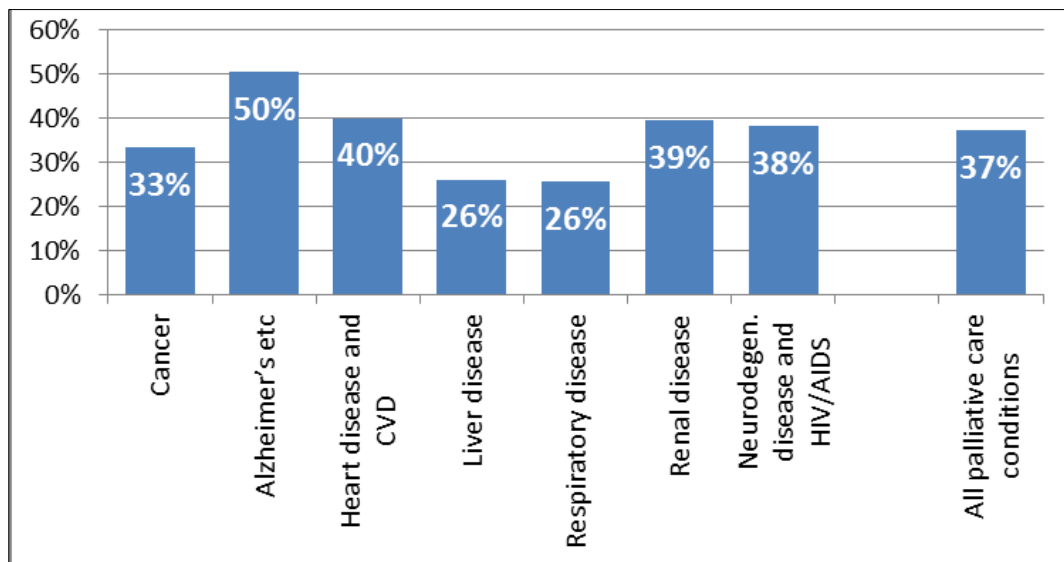
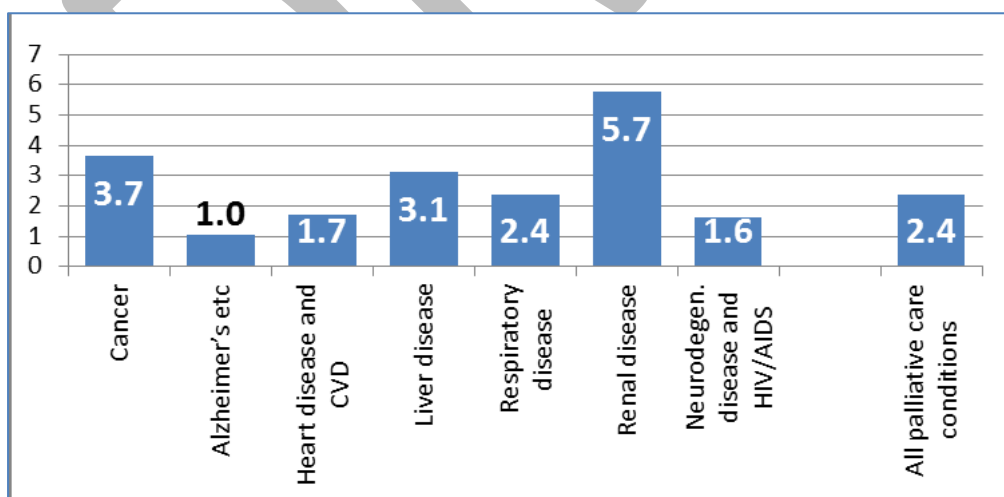


Figure 12 uses the same categories of disease, but this time looks at the average number of admissions for each disease category. Although renal disease is responsible for comparatively few deaths (all genito-urinary disease accounted for 113 out of the 6,115 death in 2015), it is striking that the average number of admissions was nearly six. Cancer is a major killer however, but cancer patients had 3.7 emergency admissions on average – perhaps suggesting that there better support processes are in place for cancer, that could y be learning opportunities to be applied to end of life care for other conditions.

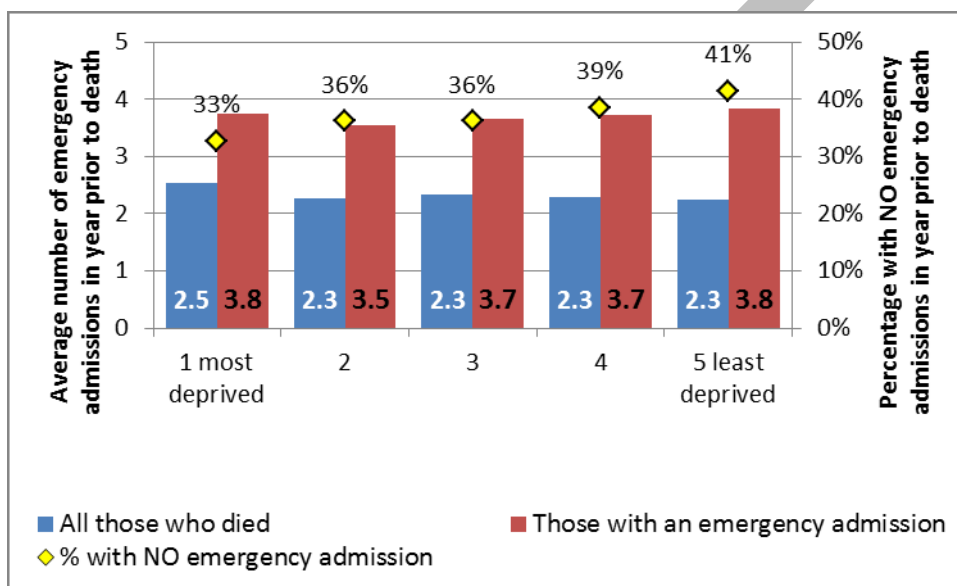
Figure 12: Average number of emergency admissions in last year of life



It is important that we give consideration to any inequalities that may exist in relation to end of life care. Figure 13 considers the rate of emergency admission by deprivation. People who had lived in a more deprived area were more likely to be admitted as an emergency than those who lived in a less deprived area. The percentage that had no emergency

admission ranged from 41% in the most deprived quintile of areas to 33% in the least deprived quintile. There are a number of possible reasons for this inequality. Firstly, it could be because predominantly deprived areas are in our more urban areas, where access to District General Hospitals is easier. Secondly, it may also be because people in more affluent areas have more financial and social capital, and more access to information than those in deprived areas. They are therefore more likely to be able to make appropriate preparations that help avoid emergency. Thirdly, the inequality may reflect the nature and complexity of the patients' illness. We know that people who live in the more deprived areas of Somerset experience a higher prevalence of almost all conditions, we also know that they are significantly more likely to experience multimorbidity.

Figure 13: Emergency admissions by deprivation



Alzheimer's/dementia deaths place the least burden on emergency admissions and those that produce the most are kidney disease, cancers and liver disease. The latter are more linked to lifestyle factors such as smoking/obesity/alcohol and are strongly associated with deprivation. It is no surprise therefore that the emergency admissions are higher for people who live in areas of higher deprivation. There are two ways of reducing emergency admissions, whether they are at end of life or not, the first is to detect disease early and manage the condition proactively where possible, the second is to prevent the condition in the first place and therefore the need for an emergency admission. There is scope to reduce emergency admissions by placing a greater focus on both of these forms of prevention. As highlighted by the Reform think tank for the NHSⁱⁱⁱ, effective preventative activity, which does not further increase inequality, needs to be done systematically and at scale and pace.

Inequality in end of life care is not only in relation to deprivation, of course. The Care Quality Commission looked at the outcomes for different groups in 2016^{iv}. Gypsies and travellers, and people whose first language is not English, found it harder to have their wishes met. People with learning difficulties need more time and preparation to understand the options open to them at end of life, and also need to be given more time to express their wishes. People with Down's syndrome are at increased risk of developing dementia, and those with both conditions will often need an extended period of support to express what they want to happen to them.

Identifying End of Life

In order to make preparations for death, there needs to be an assessment of when it is deemed that a person is at the end of life. This, like all predictions, can be hard to do. The progress of cancer is often rather predictable (which helps in end of life planning); the Care Quality Commission identified 'people as conditions other than cancer' as a group who may not receive the best care as a result. Dementia can progress very slowly and it may be hard to know the right point to shift from managing the condition to preparing for death.

The Gold Standards Framework (GSF) developed by the Gold Standards Framework Centre in End of Life Care, aims to promote quality, coordination and organisation in end of life care, leading to better patient outcomes. The GSF formalises best practice and provides an indicator of what 'good' looks like in end of life care.

The framework gives clinicians three ways of identifying whether a patient should be treated as being at the end of their life. One of them is a list of general indicators as seen in Table 1 below.

Table 1: General Indicators of Being at End of Life (Gold Standards Framework)

- Decreasing activity – functional performance status declining (e.g. feeding, bathing, grooming, dressing, continence, toileting, mobility & coping with stairs), limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l (this blood indicator shows poor liver function)
- Considered eligible for DS1500 payment (Disability Living Allowance or Attendance Allowance for the terminally ill)

The second way uses specific indicators for particular conditions such as the development of secondary malignant growths for cancer, speech problems in neurological diseases and incontinence for dementia.

The third, and simplest test combines the various indicators with clinical judgement in the 'surprise' question:

'Would you be surprised if the patient were to die in the next few months, weeks, days?'

If the patient shows the general or specific indicators, or the answer to the 'surprise' question is, 'no', then the clinician or carer should go on to consider what measures 'might be taken to improve the patient's quality of life now and in preparation for possible further decline'.

The next part of this section considers what some of those measures may be, starting with palliative care.

Medical support - Palliative Care

It is worth drawing out here that the decision to treat an individual palliatively should ideally involve the patient and/or family however care planning for individuals who have lost capacity is rarely done and therefore the responsibility for decisions relating to treatment rests with the senior clinician. In the community this is the GP, but discussions should also involve the family wherever possible. Often decisions are made to treat people rather than manage them palliatively which may not be in their best interests. This issue will be considered further later in this report.

It is important that when discussing treatment options with people that we focus on what could be done as well as what might not be done so patients and families can make an informed decision about the options. For example, when discussing an admission to hospital with someone at the end of their life, what could be done for them at home if they chose not to go to hospital should be discussed also, such as pain control etc. Sometimes there is a belief that agreeing a ceiling of treatment escalation means there will be no more treatment at all.

Much of the medical treatment given to people with life-limiting conditions will, necessarily, be specific to that condition. We will not consider the condition-specific treatments here, important as they can be to the individuals concerned, but focus specifically on what's termed 'Palliative Care'.

There are a number of treatments that come under the umbrella of 'palliative care', which try to reduce the painful and unpleasant effects of disease, or of other treatment, rather than trying to cure the illness. Palliative care puts more emphasis on maximising the quality of life than extending its length (although this may be an effect). It is often provided alongside more conventional 'treatment', such as chemotherapy for cancer. By reducing the impact of pain or discomfort it can enable patients to live something closer to a normal life. This can also help the patient's carers, and might make the difference between being able to live at home or needing to be in hospital.

In his book *Being Mortal*, Atul Gawande describes the treatment of an elderly patient with many long term conditions, including the cancer that would eventually lead to her death. The cocktail of drugs she received made her condition even more complex. When she was treated by a gerontologist, who looked at the needs of the whole person rather than the individual illnesses, it became clear that her greatest distress came from the state of her feet, which reduced her mobility and so her independence. Treating her feet, rather than the more 'serious' conditions, did not extend her life, perhaps even the reverse, but contributed far more to the quality of the life she had left.

Often in medicine, each specialty treats the patients' range of needs, illnesses and symptoms independently, it's the way medicine has developed over the years and we rely on this approach to provide us with the very best, very specialist care. There are times however, where this very specialist approach may not be best for the patient and at the end of life is potentially one of those times.

End of Life Care in Hospital

Palliative and end of life care should ensure the whole person and those important to them are cared for no matter where. Hospitals are a place of safety and in Somerset are open all hours. A feeling of safety is a key element of good end of life care. In Somerset the acute hospitals have made great improvements to their end of life care in recent years. Their shared aims are for hospice level support and care for those who choose to die in a hospital. For those who do not want to be in hospital to be safely supported either at home or in a place of care. Hospitals provide the specialist equipment and expertise when needed, and work with communities to join up the care as much as possible.

Hospitals are taking a leading role in planning for the future. An admission to hospital is likely to be a point of inflection in someone's health, such as being diagnosed with a life limiting illness or be assessed as deteriorating from an existing chronic condition. This recognition should be discussed as appropriate and the patient's needs as a person considered. Taunton and Somerset Trust has introduced a specific discharge summary for those with life limiting illness to record the start of these conversations and allow community practitioners - professional and volunteer - to continue this 'what is important to you' approach when back at home. Yeovil District Hospital has strong links with the symphony complex care teams who can also aid whole-person care and facilitate wellness. This planning starts an approach that can be supported by projects such as the Marie Curie conversation volunteers who consider the person and their thoughts by asking, amongst other key questions, 'What is important to you now and in the future?' They are trained to elucidate and communicate wishes and wants for end of life care which can enhance the professional decisions within advance care planning. This approach enhances a person's dignity in ensuring they as a person are communicated throughout their care, wherever it is taking place. This home based, non-clinical work is led by the person themselves.

Drug treatments

These can reduce the impact of, for example:

- Pain
- Nausea and Vomiting
- Breathlessness (Dyspnoea)
- Respiratory Tract Secretions
- Restlessness and Agitation

Whilst these are rarely life-threatening in themselves, they can all be the most noticeable effects of the terminal illness and be the greatest contributors to poor quality of life for the patient, as well as family and carers. They can also arise suddenly and distressingly, so, administration of drugs such as Midazolam for breathlessness for example can be hugely comforting.

Many people, especially perhaps cancer patients, may need palliative drugs such as opiate painkillers delivered continuously. This is typically done using a syringe driver, one of which is shown in Figure 14. Although far from necessarily the case, they are associated by many people with the final stage of illness, with a perception that once set up they will remain in place until the death of the patient. Other treatments, such as steroids and sub-cutaneous fluid, can, with training, be administered at home by family members.

Figure 14: Syringe Driver (Source: Oxfordshire CCG)



Despite the benefits that can be gained from such drug treatments, our expectations have to be managed. Pain can be treated and minimised but no physician can guarantee a painless death, conversely, the grief of bereavement should not be added to by feelings that a loved one has endured unnecessary suffering. Good communication – reassuring the patient and, even more, the family, that the best possible care is being provided is the key to ensuring this balance.

Providing palliative medicine is often rather more complex than other medicine, and there are a few techniques that make it easier and safer.

- **MAR charts (Medicines Administration Record).** This tells paramedics, called to someone's home at the end of life, what drugs can (and can't) be used
- **Just in case boxes.** These contain the correct medicines to treat the patient at home.
- **Message in a Bottle:** 'a sticker on your fridge and the inside of your front door tells paramedics that a bottle can be found inside the fridge. This will contain essential personal and medical details. Bottles are free of charge and can usually be obtained from your local chemist'^v.
- **MedicAlert:** a registered charity that provides an identification system for individuals with medical conditions and allergies. This is usually provided in the form of a bracelet or necklet, which you purchase. The scheme is supported by a 24-hour emergency telephone service^{vi}.
- **'Comfort calling'**. This is when GP, nurse, or out of hours doctor calls can give reassurance, even if no new treatment is needed.

'Self help' as part of Palliative Care

Palliative care need not be simply medical. As the Motor Neurone Disease Association describe:

'People living with MND have found the following helpful:

- *doing something physical, like gardening, with assistive equipment to help you stay active for as long as possible*
- *planning a trip, event or holiday (many travel providers provide accommodation adapted for people with disabilities)*
- *seeking out experiences with family and friends that will provide lasting memories*
- *using speech and communication aids to help you maintain communication and social contact should your ability to speak and gesture be affected*
- *listening to music or going to music therapy sessions*
- *having physiotherapy, with a qualified physiotherapist who has experience of MND*
- *having hydrotherapy, where exercise is assisted and supported in water to help you move and flex joints safely*
- *trying one of the many complementary therapies with a qualified and registered practitioner'*

We will consider the ways in which families and communities can provide tremendous support to people at the end of life further in this report however, it is clear from this list that there are many forms of help that do not require medical intervention from clinicians.

Individuals facing the end of life can have many things to deal with, from examining the meaning of life to practical matters of finance and planning. These issues can feel overwhelming and it's important that a wide range of patient concerns are considered during palliative care. The section below outlines the Integrated Palliative Outcomes Score^{vii}, which brings these together in a single, simple form.

Integrated Palliative Outcomes Score

Firstly, patients are asked what their main concerns are, of whatever type. This 'open' question is important, as it puts the patient at the heart of the assessment. Whatever the medical conditions may be, if the patient is most concerned about the welfare of a pet dog, for instance, then this is what has the greatest impact on wellbeing. There is a second question that asks about the severity of symptoms such as drowsiness and shortness of breath. The remainder of IPOS moves on to a wide range of potential concerns, as shown in Figure 15.

Figure 15: Questions from the Integrated Palliative Outcomes Score

- Q3. Have you been feeling anxious or worried about your illness or treatment?**
- Q4. Have any of your family or friends been anxious or worried about you?**
- Q5. Have you been feeling depressed?**
- Q6. Have you felt at peace?**
- Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?**
- Q8. Have you had as much information as you wanted?**
- Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)**
- Q10. How did you complete this questionnaire?**

The wider use of IPOS in Somerset, ideally undertaken weekly, offers a good way of tracking a patient's wellbeing that may not be the same as the purely 'medical' process. Even more helpfully, perhaps, it can help open up the difficult conversations that can really help understand the patients' needs. It reminds professionals that they are treating human beings, making it harder to fall into the trap of treating symptoms rather than the person. It may even help give professionals the bravery to speak honestly about a prognosis. For patients, it may be a chance to raise issues that can be causing considerable concern but that seem to be outside the remit of the specialist looking after them. Many end of life care professionals take a consistently broad view of patient wellbeing, and have a strong desire take on responsibilities relating to wellbeing as well as medical needs.

Providers of End of Life Care

End of life care is wide ranging and stretches far beyond the traditional NHS organisations. Below is a summary of some of the main support for end of life that is provided outside of the NHS.

Carers

Supporting the broad range of needs for someone at the end of life takes a lot of work. And the bulk of that effort tends to fall on family carers – typically, but not exclusively, a spouse or children. Carers in the family help people stay at home and reduce emergency admissions. This is consistent with the 'just in case' admissions of rural elderly identified in last year's JSNA on rural Somerset: whereas for most age groups there are higher admission rates from urban areas, reflecting generally greater health need, the rates are higher from rural areas for the over 75s. The isolation of older rural people means clinicians and paramedics admit them at a lower threshold than for people living closer to acute hospitals.

As a former GP who had also cared for two close family members at the end of life told us;

'Being a carer is a wonderful thing'.

But it is exhausting work, and formal support can be limited: as someone else described it:

'this very poorly paid 24/7 job, lots of forms to fill in, but bear in mind, you don't get any holidays, there are no days off, no clock watching, work every weekend, work every bank holiday, oh yes, and don't forget the night shift'

Another said that the formal support available means:

'Carers are only entitled to four nights sleep a week'.

There is no doubt caring for someone is a challenging and demanding role. The changing patterns of health needs that we described in the introduction – more people living with long term conditions – affects carers just as much as the cared for and carers themselves often have their own long term conditions to manage as well as managing the needs of their loved ones. In addition to carers pre-existing conditions, the health of carers themselves can deteriorate as a result of caring for another individual, in particular the mental and physical health impact of isolation and loneliness can be a significant determinant of carers' health and wellbeing. There are approximately 43,000 unpaid carers in Somerset (we do not know how many are caring for people at the end of life). Of these, 3,500 are in bad or very bad health, and of these 1,500 provide at least 50 hours of care each week.

Voluntary carers, overwhelmingly family members, make an invaluable contribution to end of life care, and are frequently in great need of support. Supportive, compassionate communities can help carers in practical ways, such as cooking meals or night-sitting (for which someone might have to pay £180), but also in maintaining social contacts for people who can otherwise become isolated.

Employers, too, have a role in supporting carers. Good employers can help carers through flexible working arrangement, signposting to the sources of support we describe in this report and, when the time comes, helping the bereaved. As we have seen, caring for someone who is terminally ill is time-consuming and exhausting, and can take people away from work for a long time; a considerate employer can help a carer return to work at their own pace and resume their contribution to society.

Hospices

The modern hospice movement began with the work of Dame Cicely Saunders in the 1960s. She recognised that beyond the medical, palliative, element of treatment, the whole person's psychological and spiritual needs, and those of their family, needed to be taken into account. Hospices in Somerset are charities and are therefore not an NHS organisation. They do receive funding from the NHS for their services but they principally rely on money raised through donations, and their charity shops.

Hospices are not only concerned with cancer, despite the common public perception that this is the case. Cancer is important, not only because it remains the leading cause of death in the UK (if all cancers are taken together), but because it can be a condition that leads to a lengthy and relatively predictable period of decline. Palliative care for cancer typically requires symptom control, including managing the side-effects of medication that has been

prescribed to deal with the cancer itself. Such work normally takes place within multi-disciplinary teams to address the range of the patient's needs.

Although many people associate hospices with their buildings, most of the care that they provide is not residential, and all palliative care consultants are based in the community. The north east of Somerset is served by Dorothy House Hospice, and the north west by Weston Hospice. The large majority of the county's population is in the catchment of St Margaret's – in Taunton and Yeovil – and for that reason alone I will concentrate on their work in this report.

St Margaret's Hospice has 24 in-patient beds, but is typically helping with the care of 450 people at any one time. Of the 6,000 or so deaths in Somerset each year, about 3,500 will have contact with St Margaret's. The support includes much out-patient treatment: in recent years, St Margaret's has seen a fourfold increase in their contact with care homes. Some support is, of course, medical, but in line with seeing the whole person's needs, it includes help in writing 'last minute' wills, arranging weddings and preparing for funerals. Underlying this support is a desire to empower the patient, including using DVD recordings of others in the same position describing how they manage their conditions most effectively.

St Margaret's provides a 24 hour telephone advice line that has run since 2011 – necessary when the need for help can strike at any time of the day or night. It is predominantly used by patients and carers in the out of hours periods, but there are now increasing numbers of calls from care homes, too, and more staff are being allocated to the service.

Care Homes and Nursing Homes

There is a wide range of provision between largely 'residential' care homes and more intensive help available in nursing homes, with dementia by far the most common cause of additional care needed in these environments. There are a high proportion of deaths in care homes, many of which will have been associated with some form of palliative care. There is a similarly a wide range of reasons that people will find themselves in care homes at the time of death. It should not be assumed that everyone who dies in a care home is as a 'resident': it is thought that one third of the deaths are of temporary residents. A frequent pattern is that of a death in residential care being of someone with dementia as an underlying factor, even if an infection may be the immediate cause; this may well be someone who has been cared for at home, perhaps by a surviving spouse, but who can no longer manage in that environment. The move away may be prompted by a crisis, such as a fall or infection, and may be seen at the time as 'temporary' rather than 'end of life'. It is not unusual for someone to be moved to a care home due to the ability of the carer to cope, rather than the patient's illness.

Unfortunately though, even in care homes, there are cases when people are admitted to hospital inappropriately. We heard of one case where a GP had said that a care home resident was close to death, and likely to die within 24 hours. Sadly, the care home staff, confronted with the bodily changes at the end of life, did not have the confidence to let her die, and called for an ambulance. She died shortly after being admitted to hospital, but now had to be classified as an unexpected death, so her body was kept in the hospital mortuary rather than being released to the family. Unfortunately, this is a situation which is not uncommon in Somerset.

In the last 8-12 weeks of life a patient may become eligible for Continuing Health Care. This means that all care and support at home can be funded by the NHS, rather than by the County Council adult social services team. This enables more help to be given, but we heard that some people find the process of applying for CHC to be cumbersome.

As is no doubt clear already, end of life care typically involves long periods of low level illness, interspersed by occasional crises. The confidence needed to accept the progression of expected deaths, both at home and in care homes of residents should not be underestimated. More could be done to improve the planning and support of end of life to help carers and care home staff at times of crisis. Frequently at these times, the ambulance service plays a vital role, however this can often result in an emergency admission to hospital that may have been avoided. Support such as the Somerset Hospice case study detailed later in this report could provide really significant support to carers and care home staff.

Approaching death

When death is near, awareness of cultural and religious differences is significant^{viii}. Even though individuals differ, there are certain religious features, such as that in Buddhism, many will want to die with a clear mind, even if that means more pain, and in Hinduism sacred images, flowers and Ganges water may help provide the right atmosphere for the progression of the soul to the next state of existence. We heard that many of the people and families who were best able to cope with death were sustained by their strong religious convictions.

It is important that we are clear of what a normal, 'healthy', death is like. The Dying Matters Coalition, set up in 2009, by the National Council for Palliative Care (NCPC) aims to promote public awareness of dying, death and bereavement. They identify certain signs in the last few weeks, days and sometimes hours of life that indicate when someone is preparing to die (see box below). Recognising what these signs are can help both families and staff to prepare for what is to come.

SIGNS THAT DEATH IS NEAR (from Dying Matters)

When someone starts to die, these are the signs that indicate death is nearing:

- **Physical changes:** in older people, skin can become paper-thin and pale, with dark liver spots appearing on hands, feet and face. Hair can also thin and the person may shrink in stature. Teeth can discolour or develop dark stains.
- Their **external world begins to diminish** until the dying person no longer wants to leave the house or their bed and may not want to talk very much. Their mood, character and behaviour may change. For example, some may become uncharacteristically anxious. Others who have held atheist views may suddenly want to explore religious or spiritual teachings.
- Increased **sleep:** the person begins to sleep for long periods. This can be distressing for relatives, but it's important to understand that even the mildest physical exertion for someone approaching death can be exhausting, and for the moment all effort is being put into staying alive. Nearer the end, the dying person may increasingly drift in and out of consciousness.
- Appetite **reduces:** the body knows it no longer needs fuel to keep it going so those who are dying often lose their desire to eat or drink. They can begin to lose weight, sometimes rapidly. It's important not to force food or drink onto someone who no longer wants it. But do take guidance from the nursing staff.
- **Changes of expression:** the person may start to talk about 'leaving', 'flying', 'going home', 'being taken home', 'being collected', 'going on holiday' or making some kind of journey. They may also begin to express heart-felt gratitude to their carers and to their family as a preparation to say their farewells.
- Special **requests:** the dying person may want something special such as to visit a particular place, or to be surrounded by their favourite flowers. They may want to hear certain music, to have family photographs nearby or to make contact with someone who has been important in their lives.

Bereavement

Bereavement, and care for the bereaved, is an important topic in its own right and applies at least as much to those sudden deaths, or deaths of young people, as to older people dying with long term conditions who are the subject of this report. Care for those who are (or know they soon will be) bereaved is an important part of end of life care. It starts with advance care planning and legacy work. A person needs to consider what their legacy will be; what stories they would and perhaps would not like to be told - even to people they will never meet. As they plan for their death and express their wishes, this is hard. It will allow those who will care for them to ensure they have the best possible individualised care as they die. Without this planning people will always try to their best but may not engage an individual's wishes to a full extent. This can adversely affect the bereavement of their loved ones. Bereavement should be considered as a process which leads to establishing and showing resilience toward a 'new normal'. A 'normal' when a person builds a life after the death of another, when the bereaved person will function in society and so reduce the burden on social and statutory networks. Good bereavement care, either facilitated or delivered, should be considered preventative activity for poor mental health. The Gold Standards Bereavement Care tools provide guidance and training, particularly to improve the experience of those whose loved ones die at home rather than hospital.

Figure 16: Immediate tasks on bereavement (from gov.uk website)

1. Overview

There are 3 things you must do in the first few days after someone dies.

- 1 Get a medical certificate from a GP or hospital doctor. You'll need this to register the death.
- 2 [Register the death](#) within 5 days (8 days in Scotland). You'll then get the documents you need for the funeral.
- 3 [Arrange the funeral](#) - you can use a funeral director or arrange it yourself.

You may be able to use the [Tell Us Once](#) service to report a death to most government organisations in one go.

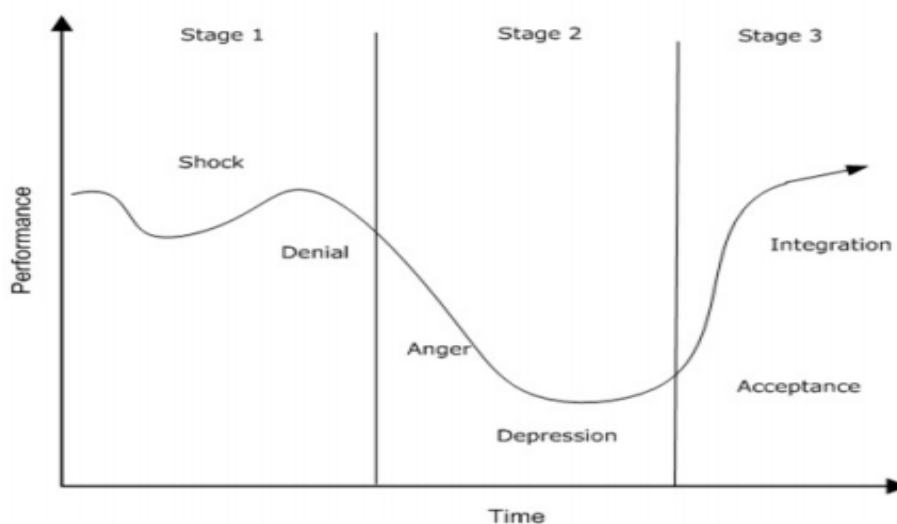
You don't need to deal with the [will, money and property](#) straight away.

St Margaret's Hospice is one agency that supports the bereaved. This includes help with the practicalities such as those immediate tasks shown in Figure 16 and longer term issues such as getting back to work and probate. (The six month time limit for probate may be a major source of stress and worsened mental health for some people). St Margaret's also helps with the potential isolation of the family, changes in family dynamics and risks to mental health – beyond the inevitable grief – that can be associated with bereavement. Other voluntary agencies, such as the Citizens' Advice Bureaux and Macmillan (founded in Castle Cary) are also involved in providing help.

Somerset's approach to bereavement care is less coordinated than it could be. Commissioning has attempted to ensure a support service is available to primary care, but this may not be able to cater for needs associated with clinical incidents, unexpected or traumatic deaths. It is challenging to describe fully a simple grief service or pathway for people who may need support beyond normal and healthy grief. All families will experience a death. Not all will need extra help in recovering their 'normal' after it, but for those who do, local services should be integrated and complementary so people can access appropriate support when needed.

Figure 17 shows the 'change curve'^{ix}, which shows a typical route taken by someone through a traumatic event, such as bereavement. It is thought that 'Everyone goes through these stages. But not consistently, not at the same pace and sometimes not even in the same order.' (*Palliative care professional*).

Figure 17: The Kübler-Ross 'change curve'



The bereavement emotions shown in Figure 17 can be overwhelming, and are hugely different from each other. Care for the bereaved requires great patience and great sensitivity to someone's varying needs. These may vary with different cultural or religious traditions, such as the speedy burial of the body in Islam and Judaism that does not apply in Christianity. They may also vary with personal preference - for some people, swift removal of reminders of the person who has died can be part of the coping process. This may be clothes, for instance, but also equipment associated with the last months and days, such as 'hospital' beds and lifting equipment. For others, though, a degree of continuity can be important, and well-meaning carers wanting to remove this equipment can be intrusive and distressing.

Bereavement is a huge subject in itself, and can only be touched on here. But importantly, how someone dies can have a big impact on how their family and friends are able to cope in their grief, and a dignified death is clearly easier to come to terms with. For some bereaved, grief can become entangled with concern about poor care – real or perceived – in a painful and angry mixture. Dame Cicely Saunders said

'How people die remains in the memory of those who live on.'

This is an important message to be kept in mind by all who care for the dying. In public health we stress the value of prevention; that is usually in preventing ill-health but applies equally to preventing unnecessary distress.

Summary

I hope I have given some flavour of the range of activities that come under the umbrella of 'end of life care', from the medical, through to the social and emotional support provided by carers and families, and to the needs of those carers and families when they have to come to terms with the death of a loved one.

The prospect of our own death, or the loss of a family member, are experiences as profound as we ever face as human beings and the above only gives a superficial description of some of the issues involved. In the following sections we hope to show how working together, drawing on community resources and making early preparations to prevent more serious consequences later, can make the inevitable end of life more acceptable and bearable.

DRAFT

SECTION 3 – How could we improve the end of life experience in Somerset?

Public health is concerned with the health and wellbeing of whole populations. Of all ‘health conditions’, death is the one that every one of us will experience and should therefore rightly be considered, not only on an individual need basis, but also from a population basis. Taking a whole population perspective on end of life can help us all think about the ‘big picture’ of end of life, the preparation for it, the care that is provided to the individual and support to the carer and family. In preparing this report many examples of good practice have emerged in Somerset as well as areas where we could do much better. In this section we will consider what more we could do as a county, drawing on our own local experiences as well as good practice from elsewhere. We have grouped these proposals under the headings of supportive communities and being prepared and working together

Supportive Communities

A survey by Dying Matters in May 2017 found that only 16% of people in this country thought that end of life care should be a matter solely for professionals, suggesting that as a society we are open to taking a broad view of the resources available and accepting of the notion that responsibility for end of life care lies with the whole system, not just at one particular door.

Communities are starting to be more proactive in taking more responsibility for improving the health and wellbeing of their local population, but matters to do with death, dying, loss and care in communities is not yet widely considered.

A Compassionate Community approach helps to shift our thinking from a largely traditional medical approach to end of life, to an approach which considers a greater role for the community alongside medicine, in providing genuine support, care and information.

Compassionate Communities can provide support for the physical, psychological, social and spiritual challenges at the end of life, but importantly the approach also aims to achieve openness toward those affected by death, dying, and loss. We heard, for example, about Porlock, where someone collapsed at another’s funeral. This led to a community drive to fund and install two defibrillators, one at each end of the village – recognizing the time it might take some residents to get from one end to the other. Notwithstanding the value of the defibrillators, the discussion of death and the community links forged may have been even more valuable.

There is no question that compared to many other countries the NHS provides the UK with a strong and effective, publicly-funded system of healthcare for all periods of life. In other countries such as Albania, by contrast, a terminal diagnosis leads to responsibility for care being passed to the family and community. This has led to very active community networks in Albania as there is little else to depend upon. Surely the approach which would provide the best quality care would be one which uses strong community support alongside and very much in partnership with the exceptional services we receive from our NHS.

South Petherton

South Petherton, a large village between Yeovil and Chard in South Somerset, demonstrates how a community, in this case the parish, can work together to support its members, with end of life care an essential part of supporting people throughout the life course.

In South Petherton the parish council works alongside the local hospital, the GP practice, health coaches, the village agent, eight 'micro-providers' of care and a palliative care nurse specialist. The local area actively seeks out people who are more isolated in the village, often these people are isolated by their caring duties. Activities such as annual street parties are not specifically intended to improve end of life care, but the neighbourliness that this encourages has real benefits. As well as the vital business of helping foster social contact, community support can include simple but essential practical help such as walking the dog and mowing the lawn. Statutory services cannot cover all the needs of a family with a member needing end of life care: an active, supportive community can reduce the reliance on these services.

At a conference for Dying Matters Week in May this year, Tom Barber, working in communities in South Petherton as part of the Symphony project, highlighted three important elements to a community partnership for end of life care. They are:

- Information sharing in person - important in developing local relationships and ensuring there is clarity
- Local solutions to local problems – often these are the most creative and low cost
- Creating a road map for wellbeing and resilience.

South Petherton shows how end of life care is a matter for families and communities, not just the medical specialists. A Compassionate Communities approach can really help in times of considerable stress and emotional turmoil, possibly like no other part of society can.

Figure 18: South Petherton village centre



Volunteers

There is clearly already an important role played by volunteers in end of life care, but this is valuable, often rewarding work which could potentially be increased. Just as there is a shortage of suitable paid staff reported by hospices, often more volunteers are also in short supply. Greater cooperation between hospices, Macmillan, Marie Curie and others could make more effective use of the resources available.

Volunteers can contribute in vital ways that are beyond the scope and perhaps even awareness of professionals. One example is the work of the Cinnamon Trust, which provides volunteer dog walkers for housebound people with pets. This means that the pets can stay at home and contributes enormously to the quality of life of someone who is very ill.

DRAFT

Marie Curie – Volunteer Companions and Helpers

In 2014, Marie Curie launched their companion service at Musgrove Park hospital, aiming to improve the experience of people who die in hospital and emotionally support their families. By recruiting, training and supporting 25 specialist volunteers, the service provides patients and their families with emotional support and someone they can talk to at this difficult time. This also helps support the hospital nurses. The volunteers are trained in patient confidentiality, safeguarding, communication skills, and issues concerning bereavement and loss. The Service has received more than 500 referrals since it launched in July 2014 compared to a target of 75 referrals a year. The service is now offered 12 hours a day, seven days a week, including bank holidays, to all 20 adult wards within Musgrove Park Hospital, with patients often referred by nurses who notice their lack of visitors. This is, however, the only hospital in Somerset to offer the service.

“I am sure you already know that comfort and support is so much needed during difficult periods and I would like to say how grateful we were for the kindness and care shown to us”

Bereaved family member

Marie Curie volunteer helpers work in the community, giving practical support to patients at home, such as taking them to the doctor, but most of the help is simply to be there and provide emotional comfort. This can include continuing conversations about Advance Care Planning that started in hospital, in a more relaxed atmosphere allowing for clearer thought. The visits are usually at a regular time as best fit the patient's needs.

Such volunteer support involves 'coming alongside people', and 'de-medicalizes' the patient's condition. Talking about oneself as a person, talking about poetry or the news, rather than just an illness, gives identity and dignity. But it is not always easy, and at the base involves a recognition that 'We can't fix it'. Volunteers need to be trained, and local businesses support by offering rooms for this to happen in. But more resources are needed, and the companion service cannot be made available overnight when, as we have seen, things can be at their hardest.

As ever, this can all be rewarding for the volunteer as well.

‘A quite unexpected “benefit” I have experienced on occasions, is a deep sense of profound peace and tranquillity, which comes from sitting quietly for up to three hours, often just gently holding a patient's hand and reassuring them of your presence.’

Companion volunteer.



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Companion volunteer.

Housing and homelessness

The links between housing and its impact on health are well established and this applies equally as strongly during the end of life. Well-designed housing can mean that people are not forced out of their home because of illness. Features such as wet rooms, wider doors, level access, joist that can take hoists to help lifting are of less advantage to those in good health, but come into their own for those who require adaptations to maintain independence.

There are many positive examples of where changes to the home make a significant difference to enable people to stay at home. The case below is just one example using some of the adaptations that can be needed.

'Most modern homes are not intended to be a hospital ward, but ours was for a full 12 month, or at least one and a half rooms, but where do you put the furniture that you have to move, to get the hospital bed into the family home? Somehow or other you do. This move included using the neighbour's garage because ours is full, but not with the transport vehicle. This bed also included an air mattress and with it came a Nebulizer, Oxygen Concentrator, Mobile Hoist, (try pulling or pushing this when loaded on a carpet) a Rotunda, Electric operated lift & rise arm chair, to help get the patient upright, Shower chair, (eventually, for the wet room) outdoor Wheelchair, mobile Commode and a couple of ramps for the back door, later on two ceiling hoists. Because of the Oxygen Concentrator the local fire service has to be informed that the device is in the home. Thank goodness for modern devices, like wireless door bells, the wife would have the push button bit downstairs in her bed and the ding dong bit was plugged in by my bed upstairs.'

'We got financial help to get a wet floor put in, what a difference that made to the wife, to have a decent daily shower and wash twice a day.'

I am very grateful to a member of the Somerset Engagement Advisory Group for this account.

The design of buildings has a major impact on health and independence. A greater focus on achieving Lifetime Homes Standards would for new housing, even if just for selected properties would be a significant step forward.

Homeless people have a typical life expectancy of only 55 years. Facing the end of life they are often admitted to hospital as the obvious place of safety. This may not be comfortable for them and they often discharge themselves early; hostels may be based on the idea of 'recovery' and be similarly inappropriate. However, in researching for this report, we heard of one case where a homeless man was able to work with health professionals to develop his own Advance Care Plan, and expressed clearly that he did not want to die in hospital. Instead, arrangements were made for him to stay with his brother, which he did until his death.

St Margaret's Hospice actively pursues links with the homeless population and the traveller community in the county. As Ann Lee, the chief executive wrote:

'According to Homeless Watch, for many in the homeless community, early life experiences are shaped by a difficult upbringing, whether this is related to sexual, physical or substance abuse, or even living in relative poverty with a lack of opportunity. As a result of these experiences, homeless people are more likely to have a combination of chronic physical and mental health issues and substance misuse problems, which can often mean that they require some of the most complex palliative care.'^x

Being, or caring for someone, at end of life brings many things into sharp focus, including facing challenges about the way we live our lives. The role that stronger communities can play in providing support to the dying and their families is not very different from that supporting young families or those who are lonely, we need to listen carefully to the needs and wishes of individuals and not assume that one size fits all. Planning our communities and local environments with a recognition of the ageing population structure, and consequent rise in the total number of deaths, will help us be prepared for future challenges.

Being Prepared

Whilst we all know that we are going to die, we put that awareness to one side in everyday life. There are psychological and cultural barriers to thinking about or discussion our deaths. Our lives, though, and not just at the end, may be more fruitful if we remain more aware of our mortality. Many people talk of having a 'bucket list' of things we would like to achieve or experience in our lives, one can presume that the greater this list is checked off the more accepting we may be of the end of our lives. As well as the 'bucket list' however, further preparation could help us to die with dignity and peace. In order to die with dignity we have to really know ourselves, and what we value, and communicate that to those closest to us.

Putting awareness of our death to one side means that much can be overlooked – for example we heard of a case where a couple had simply assumed that they would be buried. However, the shortage of burial plots meant that they had to rethink, and that led to new ideas about where they would want their ashes scattered. A dignified death involves respecting an individual's wishes – and only thinking and talking about death can bring them to the fore. We consider below the sort of preparation to be made when receiving a terminal diagnosis, before moving onto the more general preparation that we can all make.

Preparation for the terminally ill

The idea of a woman's choice in childbirth has become entirely accepted and having a birth plan is now the norm. The attitudes and planning relating to death however has been much slower to change. We cannot pretend that being prepared for a death will prevent it being unpleasant, painful or distressing; but it may make it *less* unpleasant, painful and distressing.

Figure 19: End of Life Choices (from St Margaret's Hospice)

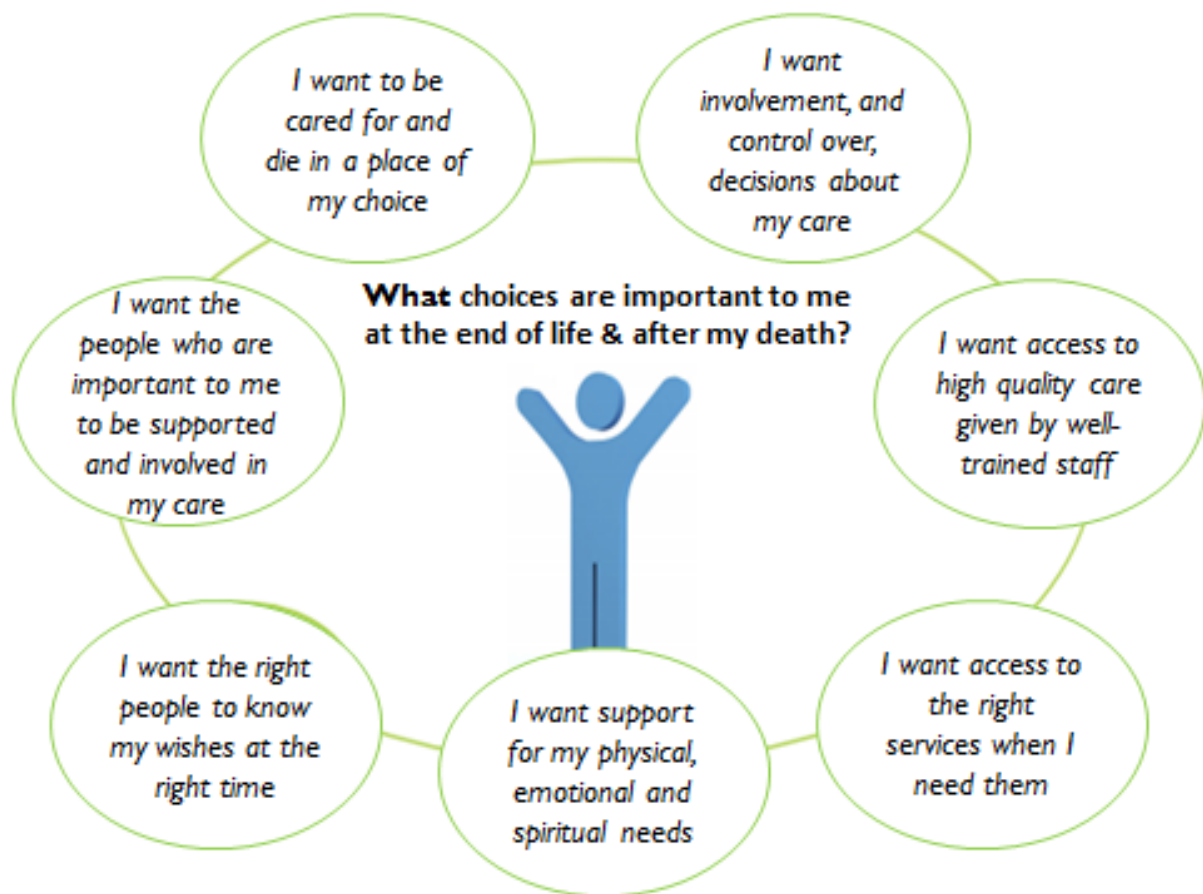


Figure 19 shows diagrammatically the sort of assertions made by people receiving end of life care, and the range of choices that can be made in preparing for death.

Advance Care Planning (ACP)

For individuals and families, the sort of preparation required is covered by the Advance Care Plan, for Somerset this is the document called 'Planning Ahead'. Of those who have completed an ACP, 80% die in the place of their choice. This is partly a result of using the ACP itself, but mostly it is because it means that the patient has thought about the future, and usually has had the difficult conversations with family about treatment. The medical elements of ACP are in some ways the least important, but planning includes the 'Treatment Escalation Plan', which shows when new treatments should, or should not, be brought in, according to medical need and patient wishes.

We heard one example of a life-long Somerset farmer who had, in the course of a family lunch, explained how he would not want to be left incapacitated and housebound as a result

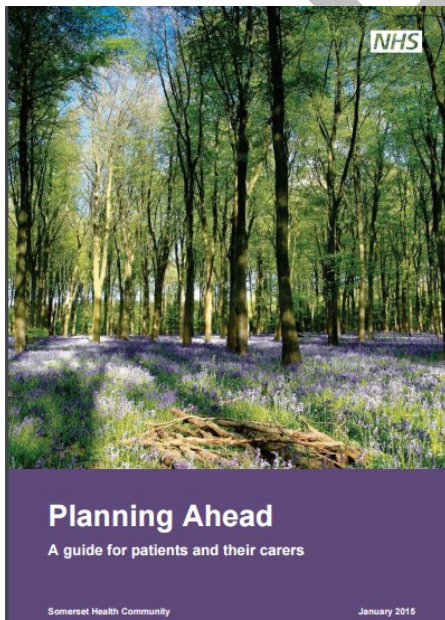
of illness. When he had a serious stroke and could not communicate, his family were able to tell the physicians that he should not receive surgery that would, at best, restore only a small fraction of the quality of his active, outdoor, life, and so he was able to die at a natural pace.

The falling proportion of deaths in hospital is thought to be linked to the increased use of ACP, and it is hoped that it should also lead to fewer admissions, fewer tests and fewer intrusive investigations in the last year of life. The efforts being made to use the 'number of days spent out of hospital in the last 90 days of life' as a good indicator of quality for End of Life Care is to be applauded.

Advance Care Planning can be undertaken at any time, of course, but tends to be done when the medical opinion is that a condition is life-limiting, which may still be some time from the end of life itself. It includes such decisions as whether to have a 'Do not attempt cardio-pulmonary resuscitation' (DNAR) notice. For some people, the acceptance of imminent death means that they prefer not to have intrusive resuscitation procedures attempted, in the belief that they are likely to add little to the length of life and that they would prefer to let the illness take its own course. This is especially the case for people whose quality of life is diminished by illness. Others, of course, wish for everything to be attempted that might keep them alive for any length of time. ACP means that professionals know how to respond in accordance with the patient's wishes.

The ACP document 'Planning Ahead' has been produced in Somerset and is the way in which most professionals encourage patients to consider and record their wishes for end of life. It works well, but for some the 'Stanford letter'^{xi} or a phone app may be better – the important thing is to do the thinking and let others know.

Figure 20: Advance Care Planning in Somerset



Simple good organisation can make life and death easier for all, with medication, contact details and advance care plans up to date, accessible and legible. Doing this 'in hours' can make things much more manageable for those working out of hours. Many of the difficult situations are out of hours, the night-time can often be the hardest, but that does not mean we need to look at out of hours services to improve matters.

The work done at East Quay medical practice in Bridgwater provides an excellent example of this, the practice has a real focus on encouraging families to use advance care planning. The practice has a robust system in place to ensure this planning is completed and all the loose ends in making arrangements are tied up. Elsewhere, other professionals also undertake a similar role including village agents and Mendip Health Connectors. In Frome, the Health Connectors undertake 'eco-mapping' of the support available, helping to link them with the people who need them.

The relief advance care planning brings to relatives and carers should not be underestimated, as well as reducing the burden of care placed on GPs. The following case study provided by Dr Ed Ford, Somerset GP and Chair of Somerset Clinical Commissioning Group demonstrates just how important they can be from a patient and family perspective.

Case Study – Provided by Dr Ed Ford

My patient was prone to seizures and had lost capacity and the family were extremely anxious about her care. We had a frank conversation about what the family expectations were for her care. They wanted her kept comfortable at all costs and appreciated that she would not want to be kept alive at all costs.

We discussed the types of treatment that would be suitable or not. We all agreed that resuscitation, admission to the Intensive Care Unit, dialysis or force feeding with a tube would not be appropriate for her if she ever required them. We did however agree that we could treat her with antibiotics for simple infections but if she were ill enough to need hospital for an infection then treatment would cause her distress and possibly be futile so we should treat her palliatively in the nursing home. We also discussed what we would do if she had an accident and broke her hip. Likewise, we agreed not to send her to hospital and keep her in bed appreciating that this would be a terminal event so we would manage it as such. Lastly, we discussed medication and what we were treating. We agreed to keep her on her anti-epileptic drugs but we reviewed all other medication and agreed to stop them unless they were managing symptoms. Hence we stopped her statins and other secondary prevention drugs.

Since this discussion, the family have been clear about the care and have felt more confident, not needing to contact me as frequently about new symptoms etc. We all know the plan and are comfortable with any potential outcome. Whilst these discussions are detailed and do take time, an hour invested for this case and many others will undoubtedly save a number of hospital admissions for the patient and provide considerable reassurance to the family.

Another potential benefit of Advance Care Planning is organ donation. Individuals may choose to donate organs, or not, for a wide range of very personal reasons. In English law, the current^{xii} presumption is that consent for donation has not been given if the patient's wishes are not known, so cases where people's wishes have not been expressed during their lifetime may result in missed opportunities that can be literally lifesaving. Practitioners will often try to raise the issue with families at the time of death, but this can be the most difficult time to do so.

An individual's legacy takes many forms, and some people find writing 'all about me' or making recordings of themselves helps them prepare for death. And even if painful initially, it can help the bereaved come to terms with their grief.

End of life care is complex, and some patients and families may be more able to negotiate their way through the system than others. Those with the fewest resources of economic and social capital are often least able to make their wishes for the end of life known or put into practice. Whilst this report aims to promote good end of life care for everyone in Somerset,

it is particularly important that support is provided to those people who are least able to make the preparations needed for the end of life on their own.

Like any plan, advance care planning is only useful if the plan is actually used and adhered to. The Goldline case study below was set up by Airedale NHS Foundation Trust as an alternative to the NHS out of hours 111 service for patients on an end of life care plan. It is a good example for Somerset to follow as this area too includes significant rural areas where the simple distance between patients, practitioners and services makes effective care a challenge. It is also acknowledged there are still people who are excluded from the benefits of modern technology who are no less deserving attention, but where possible communication solutions using technology should be supported and promoted.

Goldline

The Goldline service provides patients or carers with support 24 hours a day, every day of the year. The nurses operating the service have access to the advance care plan and, via telephone or Skype, are often able to provide the advice or reassurance needed without requiring a doctor's visit or admission to hospital.

About two thirds of the calls are during the night, which reflects the reduced availability of other professionals at that time, but also when the strains of being terminally ill, or caring for someone who is, can be the most pressing. As Stephen Lock, one carer who used Goldline, states simply:

'You do need help, you know; you really do, you can't do these things on your own.'


Figure 21: Patient calling Goldline (Airedale NHS Foundation Trust)



Goldline allows the range of professionals to see the patient's electronic records – with the patient's permission, of course. For the patient and carer, one of the greatest advantages is the sharing of information. Stephen Lock described the first time he called the Gold Line when caring for his partner Bea:

'I first rang Gold Line a couple of days after Bea had come home, just to ask about the drug that she was on. It was a fairly minor little question but it meant that we didn't need to go anywhere, we just rang one number, we didn't need to figure out "should I ring the GP, should I ring the pharmacy?"'

Figure 22: Goldline guidance to users from the Airedale NHS Foundation Trust Website

<p>Airedale, Wharfedale and Craven Bradford Districts Bradford City</p> <p>CCGs working together</p> 	<p>How can the nurses help me? The nurses can give you advice, support and can contact other services on your behalf if needed, including a doctor, district nurse, hospice or other.</p> <p>By providing extra advice and support in your own home you may be able to avoid going into hospital. However if needed, admission to hospital or hospice can be arranged.</p> <p>With your permission the nurses will be able to access your health record on the computer, so they are able to see your current situation and medication.</p> <p>They will also enter the details of your call into your health record so your usual health care team can see the details.</p>
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We know that some elderly people in rural Somerset are admitted to hospital ‘just in case’ – unquestionably well-meant, but also a further source of stress for the patient and family, as well as a cost to the already stressed health and care services.

Goldline has been shown to reduce avoidable admissions to hospital for people receiving end of life care, by shifting care away from hospitals and into the community. The impact of Goldline seems striking. Nationally only 20% of people die at home, whereas for Goldline patients the figure is 40%. Some of this effect may be because of the types of patient and condition being cared for, but even so this does suggest that similar approaches could help reduce the hospital requirements for end of life care, and most importantly provide a better death for the terminally ill, and their families, in rural areas.

Deprivation of Liberty

One consequence of failing to make preparations is ‘Deprivation of Liberty’, and the associated Deprivation of Liberty Safeguards (DOLS). This is a procedure prescribed in law where it is necessary to deprive people of their liberty who lack capacity to consent to their care and treatment in order to keep them safe from harm. Such a procedure can take time and delay providing appropriate care to people at the end of life, especially those with dementia. It is better to put arrangements in place when patients or service users are still in a position to make decisions themselves. This can be promoted through raising awareness of end of life issues.

Preparation for us all

A diagnosis of serious illness, either for ourselves or a family member, is shocking. It may also be an opportunity to rethink priorities, and make preparations for the future. It may not though, be the best time to think in a logical and rational way, it is easier to make those preparations whilst still in good health. Below are some simple actions that all adults can take to make the end of our lives more manageable for ourselves and our families. These should be advocated by professionals.

Making a Will

The most obvious preparation, perhaps, is to make a will. Without one, the process of managing an estate can be expensive but also very onerous, as described by 'Brian' to the BBC in 2016, following the death of his cousin.

'We had to pay £240,000 in inheritance tax so that hurts. If he had gone to a solicitor or a nice little company which I've used, they would have sorted all that out for him. It took two years of my life. I really took it on as a bit of a challenge really, and I felt obliged to do it because we were fairly close, and I just felt I had to do it. I think my message to everyone would be to please make a will, because then you can give your money to the people of your choice.'

A survey by YouGov in 2015 suggested that only 38% of British adults had made a will.²

Lasting Power of Attorney

For end of life care in particular, Lasting Power of Attorney can be vital.

*'A lasting power of attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf. This gives you more control over what happens to you if you have an accident or an illness and can't make your own decisions (you 'lack mental capacity').'*³

This power can be over financial affairs, or healthcare, or both. It means that decisions about end of life care, such as whether to undertake painful or risky medical procedures, can be taken by someone you have chosen, rather than by a court.

Talking to others

Practical preparations rely on us having the impact of our deaths in mind, when often it is something we tend to try to put to one side. There are increasing efforts being made by those such as Dying Matters⁴ to bring awareness of death back into our lives, as it was in Victorian times. 'Death cafes', where people can spend a short time talking about death in a relaxed atmosphere have been held in parts of the country and in Somerset earlier this year. These events could prepare and inspire us to support a compassionate communities approach, make our own preparations and work together to enable more people to die according to their wishes.

Figure 23: A death cafe in Manchester



Working together

Providing end of life care is complicated and difficult, and requires the skills of many specialists, taking the example of Motor Neurone Disease I would like to highlight some of the complexities people at the end of life and their carers' experience.

The Motor Neurone Disease (MND) Association suggests that someone diagnosed with this terminal condition is likely to come into contact with the following 16 types of people, and to this list should be added many more including paramedics, volunteer supporters and the patient's own GP.

- MND consultant
- Specialist palliative care team members
- Neurology or MND specialist nurse
- MND coordinator
- Community nurse
- Speech and language therapist (SLT)
- Dietician
- Physiotherapist
- Occupational therapist (OT)
- Counsellor
- Psychologist or neuro-psychologist
- Pharmacist
- Complementary therapist
- Wheelchair service representative
- Social worker
- Benefits adviser

In Somerset, these people would be working for numerous different organisations, including the acute hospital trusts, Somerset Partnership, the hospices, Somerset County Council and the Department of Work and Pensions. Although 16 roles are described, there may be more than 16 people doing the work. Such a number and range of people cannot work as an effective team, they have to work as a collection of specialists and try and achieve co-ordination.

Palliative and end of life care in Somerset is adapting to integration with a consortium funded, CCG led, consultant body and increasing co-production of services which aim to wrap around a person and those important to them. Face to face care and its continuity will be improved by shared ownership and goals for end of life care. People do not do well if they are ill in isolation, services must reflect the journey of understanding, adjusting, hoping and coping when they have an illness which has shortened their life.

One of the most frustrating things for all of us is having to tell the same story many times. If it's a good story it gets tedious, if it's a story about the end of life for yourself or a loved one, it's often tied up with emotions such as stress, sadness and fear and is therefore not a story you want to be repeating too often. Quite rightly, the public generally assumes that even though professionals often work within different organisations, that shouldn't stop us talking to each other. As a carer told us:

'Why didn't the local Out of Hours Doctor know about the phone call? Was because it was diverted to the NHS Direct number, so they were not involved within the story?'

Co-ordination of care

For patients with multiple conditions the coordination of care becomes of paramount importance. Part of the success of Goldline is the coordinating role that the senior nurses are able to provide.

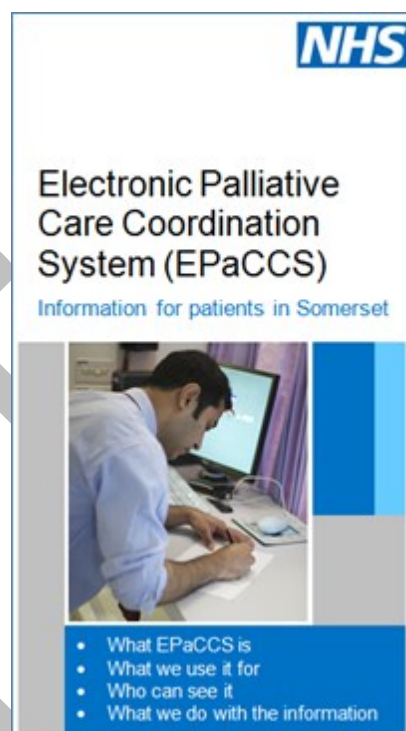
Effective coordination of care for all end of life patients in Somerset is what we should be striving to achieve. For example, Somerset is working hard to introduce a common 'Treatment Escalation Plan' to be used by all involved in care. The coordinator role can be taken by different professionals depending on the circumstance; it may be the GP, a nurse in the practice or hospital, or a professional from a hospice. Every person, and every death, is different and so we should not try to enforce a single model of care on anyone; rather we must have a framework towards which the whole system works for end of life care otherwise better coordination will be impossible.

Palliative Care Co-ordination in Somerset

In Somerset the Electronic Palliative Care Co-ordination System (EPaCCS) is used to hold information about patients' illness, treatment, next of kin and wishes in a form that can be updated and viewed by those involved in providing care. Although undoubtedly a self-selected group, it is striking that only 7% of those patients with EPaCCs will die in acute hospitals. The information held in EPaCCS is available to Out-Of-Hours staff through their operating system and includes the patient's advance care plan, indicating which treatments they do or do not want to receive in particular circumstances. Making information available easily to out-of-hours staff is a particularly good way of reducing 'over-treatment'; in the absence of other information a physician will naturally seek to do everything to prolong a patient's life. We heard of a case where someone was administered a high dose of antibiotics and taken into hospital, only for the hospital consultant to know the next day that the patient had asked to avoid such intensive treatment at the end of life. The low rate of deaths in an acute hospital achieved by using this system is an excellent result and use of the system needs to be much more widely spread.

Unfortunately, at present, this information cannot be viewed by the hospices as they, like care homes, are outside the NHS. Perceived difficulties in sharing the right information in the right form, to the right people is an impediment to many staff working in the health and social care system. Whilst some progress has been made in recent years in appropriate information sharing, far more can be achieved help to fulfil the wishes of individual patients and their families. Sadly, not all the records needed are even kept electronically, and these paper records are often slower and more difficult to share.

Figure 24: EPaCCS leaflet



The issue of appropriate sharing of data is highlighted as a problem not just in end of life care but across many aspects of care. It is an issue significant confusion and frustration for staff and requires far greater consideration and action across the whole health and social care system. I will return to this issue in the final section of this report.

Co-ordination for professionals

Sparsely populated as it is, West Somerset has 47 people per square kilometre; New Mexico by contrast has just six. It is perhaps unsurprising that New Mexico has led the way in using information technology to bring widely separated clinicians together to support each other in end of life care in the 'ECHO' project (Extension of Community Healthcare Outcomes).

Outlines in the case study below, Hospice UK is committed to the ECHO model, as is St Margaret's locally, and this way of working is being extended across the county. End of life care requires both the expert skills of specialists and a broad overview of patient need, and technology can enable the necessary communication between all those who contribute.

*'ECHO started as a way to meet local healthcare needs. Sanjeev Arora, M.D., a liver disease doctor in Albuquerque, was frustrated that thousands of New Mexicans with hepatitis C could not get the treatment they needed because there were no specialists where they lived. He created Project ECHO so that primary care clinicians could treat hepatitis C in their own communities. Launched in 2003, the ECHO model™ makes specialized medical knowledge accessible wherever it is needed to save and improve people's lives. By putting local clinicians together with specialist teams at academic medical centers in weekly virtual clinics or teleECHO™ clinics, Project ECHO shares knowledge and expands treatment capacity.'*¹

Figure 25: Sanjeev Arora, founder of ECHO



Summary

In this section we have considered a wide range of working practices, drawing from examples of good practice locally, nationally and internationally. What is clear is that there is some exceptional practice in end of life care in Somerset but this practice is often not fully rolled out across the county.

Overwhelmingly there are three themes which emerge:

- The need for preparation is a message for all of us. It is clear that good preparation can reduce some of the stresses associated with end of life and can help increase the possibility of patients wishes being fulfilled.

- End of life is far from just a medical issue. The social, emotional, practical and spiritual support that can be achieved through the development of a more Compassionate Communities approach far exceeds what could ever be achieved through support from health and social care services and can help provide very innovative solutions to the very sensitive and diverse wishes of the dying.
- The importance of working together to achieve coordination between the huge range of specialists and carers who provide end of life care. Good communication and the ability and willingness to share information is critical to achieving this.

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SECTION 4 - Conclusions and Recommendations

'Are you able to contemplate your death and the death of those closest to you? Accepting the fact of death, we are freed to live more fully. In bereavement, give yourself time to grieve. When others mourn, let your love embrace them.'

Advices and queries (Society of Friends).

Death is very different for everyone, and sensitivity to individuals' and families' wishes is paramount in avoiding unnecessary offence. Some people may want to be fully conscious, some prefer to slip away with analgesics easing the pain. Some want the windows open, others to have their dog on their laps. Sometimes the circumstances are not necessarily or wholly in our own gift, but where they are it is a sign of respect to the dying to have their wishes fulfilled.

The bereaved, too, may have very different responses. Some will want to see bulky equipment such as hoists and 'hospital beds' taken from home as quickly as possible (even if just for practical reasons such as playing host to the wake); others need a period of delay to come to terms with the death before this is done. Some people want to get through dealing with the will and probate immediately, but for some people the six month limit on probate can be too hurried and can have a significant impact on mental health.

There are many examples of where patients and their families had been supported hugely by professionals and communities at the end of life. Although, this is a time when great sensitivity is required and what may be normal, hurried activity can seem brusque and thoughtless to the family. People in such circumstances are naturally less tolerant of bureaucracy than in more normal times. Issues such as car parking charges at hospitals, that can be annoyances on other occasions, can be deeply upsetting when visiting a dying relative. Professionals need to consider that they need to care for patients' physical, mental, social and spiritual wellbeing, which can be difficult, especially under pressure of time in the middle of the night.

Being able to die with dignity is something we would all aspire to, regardless of where we die. The quote below from one carer described his terminally-ill wife's experience in hospital is just one example, and there will be many more positive examples of where people have been supported to die with dignity, but this example shows that we have not always got this right:

'There was one occasion, a few days later, when things had slightly improved, when the bed pan was wanted and the nurse told her to soil the bed, 'because I am busy' was the answer and 'we will clean you up later'. Where has the compassion and dignity gone to these days?'

There is much that can be drawn from this report and below highlights some of the main conclusions and provides recommendations as to how we can improve end of life experience in Somerset.

For everyone

- **Breaking the taboo**

Talking about the death of loved ones is difficult, often emotional and, as such frequently avoided. Becoming more open about death can help prepare us and ease the situation when it does arise. It can help give people peace of mind and enable us to ensure we make the most of the time we have.

- **Preparation**

Making preparations, such as power of attorney or making a will, may seem morbid, but done in advance, rather than at a time of crisis, can make end of life more bearable, especially for relatives and carers. This only has to be done once and revisited occasionally – there is no need to think about it all time.

- **Realistic expectations**

We cannot expect end of life – for ourselves or our loved ones – to be painless or stress-free. Accepting that can make the tribulations somewhat more manageable.

- **Sources of support**

Whilst the range of needs at end of life is huge, so is the range of support available. In the annexe to this report are contact details of many sources of support operating in Somerset.

For Communities and Voluntary Sector groups

- **Stronger Communities**

The importance of strong, vibrant communities in providing support to individuals, carers and families at the end of life should not be underestimated. This is particularly the case in supporting carers, who can otherwise become very isolated.

For NHS and Care organisations

- **Talking about death**

There is still an understandable stigma about death, and this can hold back making the best long term decisions. End of life is, of course, a very difficult time and we can't stress enough the importance of sensitivity.

- **Sharing information**

The integration of health and care is something that we are working towards in Somerset, and end of life care is an integral part of this progress. There is a need to explore the extent to which we can share information legally to benefit patient care and maximise the opportunities. This is an issue of confusion within the Somerset system

and one whereby each organisation seems to have different sharing thresholds.

- **Using technology**

Systems such as St Margaret's Hospice Care Line, Goldline, EPaCCS and ECHO help patients, carers and professionals have access to support from health services, particularly out of normal working hours. In a large rural county, use of technology and phones to keep people connected and supported at this difficult time is paramount and should be embraced to a far greater extent by health and social care services.

- **The spectrum of care**

The medical support available in EoLC is clearly crucial and is able to reduce the pain of an inevitable process. The needs of the dying also range from the very practical, such as managing finances, to the spiritual. Support in all these issues is available but can be uncoordinated.

In summary, the principal aim of using the Annual Report of the Director of Public Health to focus on end of life was to raise awareness of the growing importance of a peaceful and dignified end of life as an integral part of the whole life course.

In 'accepting the fact of death', I hope that we can indeed make life more full but I also hope that this report can encourage us all to be sensitive and prepared.

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Sources of Support in End of Life Care in Somerset

Alzheimer's Society (Dementia)	https://www.alzheimers.org.uk/ 0300 222 1122
Dorothy House Hospice (Mendip area)	https://www.dorothyhouse.org.uk/ 01225 722 988
Dying Matters	http://www.dyingmatters.org/
Macmillan Cancer Care	https://www.macmillan.org.uk/ 0808 808 00 00
Marie Curie	https://www.mariecurie.org.uk/ 0800 090 2309
Motor Neurone Disease Association	https://www.mndassociation.org/ 0808 802 6262
NHS Choices	http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx
Somerset Carers' Network	http://www.somersetcarers.org/ 01749 836633
Somerset Choices	https://www.somersetchoices.org.uk/adult/information-and-advice/carers/end-of-life-care/
Somerset Clinical Commissioning Group	http://www.somersetccg.nhs.uk/about-us/how-we-do-things/palliative-care/
St Margaret's Hospice	https://www.somerset-hospice.org.uk/ 0845 070 8910
Weston Hospicecare (North Sedgemoor)	http://westonhospicecare.org.uk/ 01934 423 900

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Endnotes

ⁱ http://www.endoflifecare-intelligence.org.uk/resources/publications/lp_and_place_of_death

ⁱⁱ <https://discover.dc.nihr.ac.uk/portal/article/4000673/an-end-of-life-strategy-probably-improved-choice-of-where-to-die-for-people-with-severe-respiratory-disease>

ⁱⁱⁱ <http://www.reform.uk/wp-content/uploads/2017/03/Brochure-Web.pdf>

^{iv} Care Quality Commission, A different ending, our review looking at end of life care (2016) (www.cqc.org.uk/news/stories/different-ending-our-review-looking-end-life-care-published)

^v <https://www.mndassociation.org/wp-content/uploads/2015/07/eol09-advance-care-planning-and-advance-decisions.pdf>

^{vi} www.medicalert.org.uk

^{vii} www.pos-pal.org

^{viii} <https://www.stgeorges.nhs.uk/wp-content/uploads/2017/01/Faith-at-end-of-life.pdf>

^{ix} Kübler-Ross, *On death and dying*, 1969.

^x Life - And Death - On The Streets | HuffPost UK. Available at: http://www.huffingtonpost.co.uk/ann-lee1/life-and-death-on-the-str_b_13167898.html. (Accessed: 24th May 2017)

^{xi} <https://med.stanford.edu/letter.html>

^{xii} An 'opt-out' system was proposed by the Prime Minister in October 2017.